出國報告（出國類別：開會）

第 17 屆歐洲緩和安寧療護協會國際研討會

服務機關：台中榮民總醫院
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摘要

研究背景：

儘管癌症治療在醫療技術提升之下快速發展，自1982年以來癌症卻始終長居台灣十大死因的第一位；當面臨高致死率且不可治癒的疾病時，大眾越來越重視如何於生命末期維持良好的生活品質，也使安寧緩和醫療照護逐漸成熟。目前已知國內外研究探討關於癌症末期照護品質的評估，指標包含：死亡地點、接近死亡的階段仍接受化學藥物治療、入住加護病房、頻繁於急診就醫、接受心肺復甦術等。然而未曾討論過安寧緩和醫療照護對末期病人的決策自主權、多重用藥和過度的維生醫療的影響。

研究目的：

探討末期癌症病人接受安寧緩和醫療對照護方式所產生的影響，尤其是針對病人的決策自主權、多重用藥和過度的維生醫療的影響。

研究方法：

本研究為回溯性分析，收案對象為台中榮總於2010-2019年死於末期癌症的病人，依病人接受安寧緩和醫療照護與否與種類，將病人分成三組：(1)接受安寧緩和病房照護、(2)接受安寧緩和共同照護、(3)沒有接受安寧緩和醫療照護，主要的研究指標是病人「不接受心肺復甦術」同意書的簽署方式、死亡地點、接近死亡時藥物使用數目、人工營養及流體餵養的給予變化。

研究結果：

本研究共收集了8719為癌症末期病人，其中2097位(24.05%)曾經住進安寧病房、2107位(24.17%)接受安寧緩和共同照護、4515位(51.78%)未有安寧緩和照護團隊介入。曾經住進安寧病房的族群有明顯較高的「在院死亡」發生率（80.83%, vs 50.17% and 45.16%, $p<0.001$)及自行簽屬「不接受心肺復甦術」的比例（48.58% vs 26.22% and 22.38%, $p<0.001$)。而在死亡前28天內，曾經住進安寧病房及接受安寧緩和共同照護的族群，有明顯較少的癌症藥物使用、藥物總使用數目、及人工營養及流體餵養的給予。

關鍵字：安寧緩和醫療、自主權、維生醫療

一、 目的

近年來，隨著全人醫療觀念之推廣，末期病人之安寧療護已成為醫療品質評估之指標項目之一。本次秉持學習以及分享本院成果之心情，參與安寧療護重大國際會議，目標吸取相關新知，用以照護臨床病人，並同時將本院之研究成果與國際分享。

二、 過程

本次會議因應COVID疫情，採取線上視訊會議之形式，本次會議雖與過往之實體會以形式有所落差，無法實際與各國專家當面討論。但會議參與狀況仍然反應熱烈，線上與會人數達數千人，本人亦於110/10/6-10/8參與線上視訊會議。

三、 心得

本次海報主要關於癌症病人在生命末期的激進治療及照護(ACCEoL)，隨著醫療進步發展，各種癌症治療都已有專家提出overtreatment的觀念，ACCEoL的議題更是越來越令人擔心，其定義為損害生命末期時生活品質的過度激進治療。如果我們能夠辨認出哪些病人最容易接受到ACCEoL，將會是改善癌症末期病人照護的基石，也是本次發表主題中最核心的部分。其實各式醫療品質的研究最困難的部分一直都是如何定義「品質」本身，目前除了各氏量表也逐漸將臨床上不同的指標放入。在這次的會議中就有不只一篇研究利用類似的觀念在不同的主題，再帶入臨床醫療系統的數位化資訊，在重視大數據的今日越來越多文章著重在類似主題。

四、 建議（包括改進作法）

於本院進行ACCEoL相關研究，辨認出與ACCEoL的臨床相關因子有助於我們更清楚瞭解疾病過程，並且降低ACCEoL的發生率，給予癌末病人更好的生活品質及減少家屬的哀傷。安寧緩和照護對於癌症病人及家屬來說，往往都是供不應求。

五、 附錄

無

PALLIATIVE MEDICINE

EAPC Abstracts

Welcome from the EAPC President

Dear Colleagues, Dear friends,

On behalf of the EAPC Board of Directors, and as President, I am delighted to welcome you to our 17th EAPC World Congress. For the second year in a row, we are hosting this congress online. As many of you will know this congress was originally planned to take place in beautiful Helsinki in May 2021. In contrast to last year, this year we have had more time and experience to plan and prepare for this online event. We have carefully analysed your feedback from last year and based on this have improved our congress platform to ensure that the EAPC congress 2021 will more than meet the needs and expectations of our very discerning congress-going delegates.

It has been my honour to work with a dedicated group of colleagues, who have worked tirelessly to bring this programme to fruition. We are also extremely grateful to you for your ongoing support. We understand the challenges that many of you have faced working clinically throughout a global pandemic and we would really like to thank all of those who submitted one of nearly 700 abstracts.

I would like to especially thank the Helsinki team (with a special mention of Kaisa Rajala and Kaisa Halinen), their role in the conference organisation changed from being our local Helsinki organisers to helping with the online congress. For those of you who like me, who are disappointed to not have had the opportunity to visit Helsinki there is good news. . . pandemic's allowing, we are planning that for EAPC 2024 Helsinki will be the perfect place for an EAPC Congress. We are also in the early stages of planning an in person/blended congress in May 2023.

There are many other people to thank for helping to bring this online event to fruition. Our Scientific Committee and particularly our dedicated Chair, Fliss Murtagh; our debt of thanks goes to each of them for the hard work and commitment over many long hours. We would also like to thank our Conference Partner, Interplan and Elke Jaskiola for supporting us through difficult times. We are extremely grateful to Gavin Henrick and his team at ITS for their support with the congress platform, technical support and much more. Of course, my personal thanks to the EAPC Head Office team, Julie, Cathy, Avril, Claudia, Joanne and for the logistics, organisation and managing all the other EAPC demands at the same time as bringing a world congress online together. Finally, I wish us all a wonderful congress Online, combined with the hope that we will soon meet again in person

Professor Christoph Ostgathe
President, European Association for Palliative Care

10.1177/02692163211035909

Welcome from the Chair of the Scientific Committee

The last eighteen months have been challenging for us all, on an unprecedented scale. In this changed world, we are all of us experiencing growing demand for palliative care, major changes in palliative care practice, and increasing challenges to the delivery of palliative care services.

The EAPC 17th World Congress “Exploring New Dimensions” gives us a wonderful opportunity to support and encourage each other, gain new energies, and learn from all that has happened. There are exciting innovations and excellent progress to discover from within our palliative care community, as well as valuable contributions from colleagues and communities beyond palliative care. There is real innovation and inspiration woven throughout the programme; much to discover and learn here.

A huge thank you to all of you for the effort you have made on so many levels to attend and contribute to the Congress – I wish us the most productive, inspiring and valuable time.

Looking forward to meeting with you all throughout the Congress and beyond.

Professor Fliss Murtagh
Chair, Scientific Committee
17th EAPC World Congress Online

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PS01 (E) Massive Open Online Courses (MOOCs) to Enhance Education in Palliative Care

Abstract number: PS01
Abstract type: Parallel Session

Using MOOCs to Achieve International Dissemination of Research

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Aim: For research to have impact, research findings need to be known and implemented by practitioners. Traditionally, we rely upon conference presentations and publishing in journals to disseminate research findings, but many practitioners are unable to attend conferences (often due to the cost) or have limited access to journals. In addition, there is very little free education specifically about palliative care world-wide.

The aim was to demonstrate how free massive open online courses (MOOC) can be used effectively to disseminate research findings.

Methods: Two European funded studies were used as the basis for two MOOCs. The MOOCs ran over 3 weeks, and each course was repeated three times annually. The MOOCs included videos and a range of interactive activities. At the end of the course a certificate could be bought. Both MOOCs were evaluated by participants. Participants were asked to rank a series of recommendations in relation to the research findings.

Results: Over 12,000 people attended the two MOOCs from over 150 countries. Most participants were healthcare professionals, but also members of the public including patients. In most MOOCs there is a large attrition rate, but in these MOOCs there was a higher number of participants purchasing certificates than normal, which they were eligible for if the whole course was completed. Participants were very positive about their experience and welcomed a more globally informed understanding of palliative care. Some indicated it changed their practice.

Conclusion: MOOCs offer an affordable, global and accessible way to disseminate research findings to healthcare workers in particular. They can inform practitioners and thereby change practice. They also give researchers access to a large audience to make recommendations about their research findings.

Abstract number: PS01
Abstract type: Parallel Session

What's Online Learning Like? Experiences of a User from Lebanon

Dakessian Sailian S.[1]
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Participating in a massive open online course (MOOC) on palliative care was an exciting and novel experience. It allowed me to connect with experts in the field and participants from different countries who shared a common interest. However, being in touch with non-native ideas, values, human stories, and different methods of managing palliative care in the best interest of the patient and the family was the most intriguing. The opportunity to participate in a MOOC was appealing because it was affordable and had a self-paced learning method. However, despite its attractive elements, such as note-taking, taking photos of slides, learning about diverse perspectives, it had its challenges. The difficulties were related to managing proper time for personal development, maintaining self-discipline, poor internet connectivity, and frequent power outages.

Overall, the experience was positive and empowering. It facilitated conversation of difficult topics like death and dying with increased confidence and ease. The participation in the MOOC enabled personal reflection on the local context, cultural norms, infrastructure, and the applicability of palliative care services in a resource-limited country such as Lebanon.

Abstract number: PS01
Abstract type: Parallel Session

Using MOOCs to Develop Community Discussion Around Death and Dying

Tieman J.[1]
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Background: We are living longer with greater access to information but are not necessarily comfortable talking about death and dying. The CareSearch Project (Finders University) developed a massive open online course (or MOOC) on death, dying and palliative care. The project aim was to have at least 500 people enrol in a national online conversation about death and dying through the Dying2Learn MOOC. An embedded research study aimed to determine what effect online learning and discussions within a MOOC on death and dying had on participants' feelings and attitudes towards death and dying as measured by the Coping with Death Scale (CDS).

Methods: A constructive MOOC exploring perspectives and views around death and dying was run comprising 4 modules: how we engage with death and dying; media, literary and art representations of death and dying; medical conceptualisations; and digital dying. As well as activity and registration data, a pre-post evaluation study and a pre-post research study were conducted. A follow survey of participants was conducted six months after each course.

Results: The course was run 4 times and nearly 5,000 people enrolled. Evaluation responses showed that MOOC was enjoyable, met expectations, and gave participants a deeper understanding of death. Death attitudes were positive at commencement increasing significantly following participation in the MOOC. Death competence as measured by the CDS showed a statistically and clinically significant improvement for each of the course cohorts. The follow survey indicated 79% had talked with family and friends about MOOC content, 67% had started a conversation about death and dying at work, and 75% had looked for ACP information.

Conclusion: People are willing to be involved in online conversations about death and dying through a MOOC. MOOC participation led to people feeling more comfortable talking about death and dying and a statistically significant increase in death competence.

PS02 (A) Innovative Models of Home Palliative Care

Abstract number: PS02
Abstract type: Parallel Session

Updated Cochrane review results on the effectiveness and cost-effectiveness of home palliative care services for adults

Gomes B.[1,2], de Brito M.[2,1], Calanzani N.[3], Curiale V.[4,5], McCrone P.[6], Higginson I.[2]
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Aims: In 2013 a Cochrane review of 23 studies (16 RCTs) showed evidence that home palliative care increases the chance of dying at home and reduces symptom burden, in particular for patients with cancer, without impacting on caregiver grief. With an increased policy focus on home care and as the field grew, an update is needed. This presentation shares the decision to focus the update on RCTs and discusses its impact.
Methods: Literature scoping and analysis of the results from the original review comparing RCTs and non-RCTs informed the decision. The search strategy in electronic databases was revised to include the Cochrane highly sensitive search strategy filter for identifying RCTS in Medline and the equivalent in other databases.
Results: The literature scoping revealed the field has moved on since the original review, with numbers of RCTs at least doubling (from 16 to 32) and non-RCTs covered in two other systematic reviews. Furthermore, original review findings showed that the review questions can be answered by RCTs. For our primary aim, 5 RCTs, 3 of high quality, including 886 patients, provided evidence of increased odds of dying at home (odds ratio 1.73, 95%CI 1.28 to 2.33 in RCTs vs. 3.44, 0.60-19.57 in CCTs), with meta-analysis revealing greater homogeneity (I^2 0% vs. I^2 83%) and statistical significance ($P<0.001$ vs. $P=0.16$) in RCT evidence.
Conclusion: RCTs are the best design to minimise bias when evaluating the effectiveness of interventions and can be done robustly to assess the impact of home palliative care. A review focused on RCTs will produce a stronger evidence base to ground recommendations on home palliative care and ways to improve it.

Abstract number: PS02
Abstract type: Parallel Session

Community-Based Short-Term Integrated Palliative Care for Older People with Chronic Noncancer Conditions: A Randomised Controlled Mixed Method Trial

Evans C.[1], Elderly Optimising PalliaTive care for Older People (OPTcare Elderly)
[1]King's College London, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, London, United Kingdom

Aims: Palliative is advocated for older adults severely affected by chronic noncancer conditions, but how to deliver is poorly understood. We aimed to evaluate the impact of a community-based short-term integrated palliative and supportive care (SIPScare) intervention on symptom distress for adults aged ⩾75 years with multiple conditions and frailty.
Methods: Randomised single-blind trial to evaluate the clinical outcomes of SIPScare compared to usual care and cost-effectiveness, with a nested qualitative study on perceptions of care. SIPScare comprised person-centred palliative care delivered by multidisciplinary specialists in palliative care working with GPs and community nurses. Additional support of specialists targeted at points of escalating health-related suffering and intervention delivery over 12-weeks. Main outcome, five key symptoms measured at baseline, 6 weeks and 12 weeks, and economic evaluation. Qualitative interviews with patients/carers receiving SIPScare.
Results: 50 patients assigned to intervention (mean age 85.3 years) or control (mean age 86 years), and 26 carers. Participants lived at home (n=48) or care home (n=2) with frailty (intervention 91.2%; control 80.8%) and multiple conditions (mean intervention 3.5; control 3.6). SIPScare showed effectiveness on the main outcome versus control with medium effect size, and cost-effectiveness with reduction in symptom distress and costs. SIPScare was considered beneficial with themes of 'Little things make a big difference' of optimal management of symptoms, coupled with 'Care beyond medicines' of psychosocial support to adapt to decline and maintain independence.
Conclusion: SIPScare is a clinically effective way to deliver community-based palliative care for older adults with chronic noncancer conditions. This is a unique examination of an intervention strengthening access to palliative care at points of increasing health-related suffering. Further research is needed on wider implementation.

Abstract number: PS02
Abstract type: Parallel Session

Accelerated Transition to Palliative Care at Home in Advanced Cancer: A Randomized Clinical Trial

Sjøgren P.[1]
[1]Rigshospitalet, University of Copenhagen, Section of Palliative Medicine, Copenhagen, Denmark

Aim: The primary aim of the trial (DOMUS) was to investigate whether a systematic fast-track transition from oncological treatment to specialized palliative care at home for patients with incurable cancer reinforced with a psychological dyadic intervention could result in more time spend at home and death at home. Secondary aims were among others to improve patients' and caregivers' quality of life.
Methods: DOMUS was a prospective, single centre, randomized controlled trial (Clinicaltrials.gov: NCT01885637). Patients were randomized to receive fast-track specialized palliative care at home enriched with a dyadic psychological intervention plus standard cancer care or standard cancer care as usual. 340 patients with incurable cancer and no or limited antineoplastic treatment options were included from a comprehensive cancer centre and 258 caregivers (closest relatives) were included. Assessments took place in patients for 6 months and in caregivers for 19 months into bereavement.
Results: The main findings of the DOMUS study indicated that the intervention had no effect on time spent at home or place of death. However, the findings of the secondary outcomes indicated that the intervention resulted in improvement of quality of life, social-, and emotional functioning after 6 months. The caregivers in the intervention group experienced significantly lower symptoms of anxiety at 8 weeks and 6 months in the study period and 2 weeks after the patient's death. Further, significantly lower symptoms of depression at 8 weeks and 6 months in the study period and 2 weeks and 2 months after the patient's death were experienced by the caregivers.
Conclusion: The DOMUS model had no effect on place of death and time spent at home; however, positive effects on patients' quality of life as well as positive effects on caregiver distress before and after the loss and on partners dyadic coping were observed.

PS03 (B) Improving Care for People Unable to Self-report: The Role of Person-Centred Proxy-Reported Assessment Measures

Abstract number: PS03
Abstract type: Parallel Session

Using Structured, Person-Centred Measures for People with Dementia Unable to Self-Report to Identify and Meet Palliative Care Needs: Reflections from Empowering Better End of Life Dementia Care

de Wolf_Linder S.[1,2], Kupeli N.[3], Crawley S.[3], Reisinger M.[1], Kenten C.[3], Gohles E.[1], Ellis-Smith C.[4], Davies N.[3,5], Moore K.[3,6], Sleeman K.[4], Schubert M.[1], Sampson E.L.[3], Murtaugh F.[2], Evans C.J[4,7]
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Background: Needs, symptoms, and concerns are challenging to assess in people who are no longer able to self-report such as people living with dementia (PwD). A palliative care approach may be useful in identifying and managing unmet needs to reduce symptoms and concerns at the end of life.
Aim: To explore the role of person-centred measures in the care of people unable to self-report by i) identifying how nurses recognise and assess symptoms and needs in PwD; ii) by describing key challenges of virtual data collection using proxy assessments in PwD.
Methods:
1) Scoping review guided by PRISMA statement and databases (eg EMBASE, MEDLINE) and references of relevant papers searched; 2) Mixed method cohort study using prospective data collection to explore palliative care needs of PwD.
Results:

1) From 2028 papers, 37 relevant studies published between 2000 and 2021 identified. Pain was sole focus of assessment in 29, while 8 articles described assessment of other symptoms (eg constipation, delirium, discomfort). Nurses mostly assess symptoms by observing the PwDs behaviour during routine care. About one third of pain assessments are supported by person-centred pain assessment tools (eg PAINAD).
2) During the pandemic, data collection was adapted to virtual assessment. 16 PwD had symptoms reported to impact on PwD including pain, poor appetite, drowsiness, weakness, and reduced mobility. Challenges of collecting proxy-rated data during the pandemic include carers unable to visit PwD and care homes' staff's limited capacity to partake in research.

Conclusion: The review highlighted that evidence about how nurses assess symptoms other than pain in PwD is scarce. Nurses' observational assessment may be better supported by a person-centred screening tool to document critical observations in real-time such as the IPOS-Dem, which was found to be suitable for non-specialist palliative care settings. The pandemic has triggered the use of proxy assessments when assessing unmet needs of PwD.

Abstract number: PS03
Abstract type: Parallel Session

Person-Centred Proxy Measures: Clinical and Methodological Challenges, and Recommendations to Maximise Valid and Reliable Assessment

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Background: Measures used in routine care can support comprehensive assessment for people with dementia to inform person-centred care. As dementia advances, proxy-reported measures are required.
Aim: To maximise valid and reliable proxy person-centred assessment in care using the Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem).
Methods: Transparent Expert Consultation including a stakeholder workshop using modified nominal group technique to generate recommendations and consensus survey. Participants were international experts in dementia, palliative care and geriatrics; and Patient and Public Involvement representatives. Workshop participants generated and prioritised recommendations. Those considered contentious or with uncertain agreement were presented in the survey. Survey respondents rated agreement for each recommendation. Descriptive statistics were used for agreement and categorised according to established criteria. Thematic analysis for workshop data and free text responses.
Results: Twenty-even workshop participants generated 179 recommendations. Recommendations prioritised with high frequency were accepted (n=21), those with low priority and frequency were excluded (n=15). Thirty-one respondents (74% response rate) rated 21 recommendations in the survey. Final recommendations formed one overarching theme: *Person-centred assessment: construct, intention and relevance* and included the concept of 'being affected by' and the requirement for comprehensive assessment to 'increase awareness' of the person, despite acknowledged challenges of reliable proxy assessment. Recommendations to improve reliable assessment included multiple proxies and training. 'Action plans' should be generated to inform care.
Conclusion: To maximise person-centred care, it is important to assess the extent to which individuals are affected by symptoms or concerns. This enables an understanding of priorities to generate person-centred care plans.

Abstract number: PS03
Abstract type: Parallel Session

Assessing Palliative Care Needs in People with Dementia Using Proxy Measurement: Validation of the Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem) in German Nursing Homes

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Background: For the psychometric validation of the IPOS-Dem in nursing homes in Germany, standardised measures for assessment of palliative care needs are scarce. Therefore, symptoms and concerns observed and documented in routine care documentation are an important source of information.

Aims: To develop and pilot test a data extraction matrix for routine care documentation and test its feasibility for the validation of IPOS Dem.

Methods: Pilot study in one nursing home. Nursing home staff administered IPOS-Dem and collected demographic and clinical data at baseline and at 10-14 days. Development of an extraction matrix based on IPOS-Dem and patient charts, medication and structured assessments, with a mixed inductive and deductive approach. Interrater reliability of the final version of the extraction matrix on a random subsample, tested with Cohens' Kappa. Feasibility analysed descriptively using Venn diagrams, comparing IPOS-Dem scores with routine documentation.

Results: Data of 30 residents, average age 81 years, with advanced dementia. The extraction matrix has 13 topic areas and 94 items, covering symptoms, symptom burden, actions taken and free text. Interrater reliability in n=14 data sets was 0.78 at baseline and 0.90 at follow-up. Venn diagrams show a high overlap for symptoms such as pain and mobility. Other concerns such as difficulties eating/poor appetite were less commonly identified in routine documentation

Conclusion: The extraction matrix is a reliable tool to utilize information from routine care documentation for psychometric validation of the IPOS-Dem. Undetected symptoms and concerns in routine documentation support the use of comprehensive outcome measurements in clinical practice.

PS04 (B) Management of Fatigue in Advanced Cancer - Psychological, Physical And Pharmacological

Abstract number: PS04
Abstract type: Parallel Session

Psycho-educational interventions for fatigue in palliative care

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Aim: To present an overview of evidence (by author led narrative review) for effectiveness of psychological therapies for managing fatigue in advanced cancer.

Methods: Pubmed and Cochrane Database search covering a 6 year period from 01-Jan-2015 using relevant keywords including Cancer related fatigue (CRF).

Results: Salient systematic reviews of the literature and relevant clinical guidelines have been identified, with emergent themes and results presented in a narrative review. Whilst there is a robust body of evidence supporting the effectiveness of both Cognitive Behavioural Therapy (CBT) and Behavioural therapy (BT) based interventions, as well as psychoeducational therapies, there is less robust evidence to date on the effectiveness of a range of other supportive expressive therapies, with these studies often being plagued by smaller sample sizes. Nonetheless there are a growing number of more recent studies exploring the effectiveness of other therapies in the management of CRF.

Conclusion: Whilst Psychological care is becoming increasingly available to advanced cancer patients for symptoms impacting Quality of Life (QoL) such as CRF, and indeed a greater emphasis placed on QoL generally, it is clear that there are differences in the robustness of the evidence base to date around the effectiveness of different psychological therapies for managing fatigue in advanced cancer as discussed. Further research in this area is required, as well as improving healthcare professionals understanding of the different modalities of psychological therapy available, thereby supporting an individualized and patient-centred approach to management.

Abstract number: PS04
Abstract type: Parallel Session

Drug treatments for fatigue in palliative care

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Aim: To present a narrative review of evidence for effectiveness of pharmacological therapies for managing fatigue in advanced cancer.

Methods: Search of Medline and Cochrane Database of Systematic reviews (01-Jan-2015 to 16-Jun-2021) using key terms for Fatigue and Neoplasms.

Results: Relevant systematic reviews and randomised clinical trials were identified and main results have been summarised for presentation in a narrative review. There is some evidence for the effectiveness of methylphenidate, erythropoietin (in anemic patients receiving chemotherapy), modafanil (in patients with severe fatigue); ginseng (after 8 weeks in patients receiving chemotherapy), and dexamethasone (in palliative care patients with advanced cancer). There is no evidence to support the use of progestational steroids, paroxetine or L-Carnitine.

Conclusion: There is evidence to support the use of some drugs in some circumstances. The evidence for effectiveness is weak and further research is required.

PS05 (F) Economics of Palliative Care: New Approaches to Understand and Demonstrate Effects

Abstract number: PS05
Abstract type: Parallel Session

Trajectories of Health Care Expenditures after the Onset of Functional Disability: New Insights from Latent Class Analysis

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Aims: The onset of functional disability is a sentinel event that impacts the health care that older adults need and receive. Despite the importance of functional disability in driving health care use, there is little information about the heterogeneity of health care use after functional disability. We aim to use a Group-Based Trajectory Modeling (GBTM) approach to assess the trajectories of Medicare expenditures after incident ADL impairment.

Methods: We used data from the 2011-2017 National Health and Aging Trends Study (NHATS), an annual survey representative of older adults in the United States that is linked to Medicare claims. Cohort included community-dwelling adults who report incident disability, defined as beginning to receive help with self-care or mobility in the prior year. The date of incident disability as retrospectively reported by the respondent will be noted and is considered to be time0 for the study. Outcome is the quarterly total Medicare expenditures. We first assess the overall quarterly expenditures 1 year before and 2 years after onset of disability. We will then use a GBTM to model and characterize trajectories of expenditures the 2 years after onset of disability.

Results: We identified 1,687 adults age ≥70 with new onset of disability and at least one month of fee-for-service Medicare claims. There was an 8-fold increase in expenditures from 4 quarters before onset of disability to the quarter after onset of disability, and then a return 2-fold the baseline by the next quarter. GBTM revealed three distinct trajectories of expenditures: high (81.6%), moderate (15.8%) and low (2.6%). Both health and demographic characteristics were associated with trajectory group membership.

Conclusion: We demonstrate that a retrospectively reported marker of onset of functional disability is associated with a major increase in health care expenditures, but trajectories of utilization after disability are heterogeneous.

Abstract number: PS05
Abstract type: Parallel Session

Projecting Future Needs, Costs and Outcomes in Palliative Care: An Economic Policy Evaluation for the Department of Health (Ireland)

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Aims: The overall aim is to discuss an econometric policy evaluation of palliative care in Ireland through three inter-related research questions (RQ):

1 Future needs: What is PC/EOLC population aged 50+ in Ireland to 2050?

2 Economics: What are the associated healthcare costs?

3 Policy evaluation: How does specialist palliative care (SPC) provision affect costs?

Methods: We use data from The Irish Longitudinal study on Ageing (TILDA), government census data and the HIPE database of admissions to public hospitals. We combined TILDA and census data to address RQ1:how many people aged 50+ will live and die with cancer, advanced organ disease or dementia to 2050? We modelled health care costs associated with age, gender, diagnoses, functional limitations and health behaviours, and combined these with RQ1 estimates to address RQ2. To address RQ3, we estimated the effect of inpatient SPC on costs using difference-in-differences analysis in HIPE and the effect of SPC homecare using equivalent methods in TILDA, and we combined these effect estimates with RQ2 results.

Results: The number of deaths with PC/EOLC need rises an estimated 90% (2020-2050). The ratio of people with cancer, advanced organ disease or dementia not in the last year of life outnumbers those in the last year of life by a ratio of approximately 12:1 and this is fairly constant over time. Mean health care costs in the last year of life (2018€) with PC needs was €33,408; mean health care costs not in the last year of life with PC needs was €6,836. Hospital SPC appears to reduce cost of an admission by approximately 15%; no significant effect of homecare was found; inpatient hospice costs are high and may offset hospital savings.

Discussion: Expanding hospital SPC appears an important cost-saving strategy. Better evidence is essential on outcomes and cost-effectiveness, particularly for non-specialist and non-hospital models of care if rapidly growing population health needs are to be met.

PS06 (A) "There is an app for that" — Leveraging Technology to Advance Palliative Care to Patients and Families Across Care Settings

Abstract number: PS06
Abstract type: Parallel Session

When Digitalization Goes Viral, in the Pandemic and in Palliative Care

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Aim: Digital technologies such permeate all areas of our daily life. In particular, the corona-pandemic have spur growth in the use and implementation of digital technologies in the clinical context. This session aims to give an overview of aspects and recent developments of digitalization in palliative care.

Method: Overview on selected publications, outlook, and discussion

Results: Digital interventions range from electronic medial health records (EMR), applications (APPs), software agents (BOTs), computerized decision support systems (CCDSS), wearables, virtual reality and augmented reality. Digital approaches such as artificial intelligence (AI) can help to determine the need to involve palliative care, or to identify patients with high symptom burden or poor prognosis. (**Identification)**. During in- or outpatient treatment, digital assessments are used. After discharge from palliative care wards, Smartphone applications (apps) and wearables are investigated to prevent emergency re-hospitalizations or to strengthen outpatient care. **(Monitoring)** Psychosocial and spiritual care turns digital. Mobile apps can be used in the prevention, diagnosis and treatment of depression and gain importance in spiritual care. Virtual Reality is considered to be a promising intervention in bedbound patients. (**Therapy).** Digital communication allows isolated patients to communicate with their loved ones during the pandemic. Furthermore, digital approaches are tested to support decision making at the end of life **(communication; information sharing and shared-decision making).** During the last year, digital technologies have transformed education: teaching and training in palliative care has become almost entirely digital **(Education).**

Conclusion: Strengths, weaknesses, opportunities and threats need to be considered. Approaches in favor of patient care are warranted. A guideline by the WHO on how digital interventions can actually be applied in the interests of patients will be discussed.

Abstract number: PS06
Abstract type: Parallel Session

What do people need from technology in the provision of palliative care? Findings from user engagement and technology implementation across low, middle and high-income setting

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Aim: To present reflections from digital health development for palliative care, highlighting pathways to their development and unanswered questions.

Methods: An overview of experiences and reflections from digital health intervention development for palliative care in the UK and three countries in Sub-Saharan Africa.

Results: Experiences and resulting reflections are highlighted across three phases of digital health intervention development: i) Design (Which frameworks can guide the engagement of intended users? Which methodology is best suited to involving users?); ii) Development (How can you engage with technology developers? What principles should guide design?), and; iii) Evaluation (How are digital technologies viewed by users? Are we missing any important outcomes to determine the benefit and impact of digital health interventions?).

Conclusion: User-centred design remains critical to digital technology design for palliative care, with emerging frameworks and models to underpin research activity. Approaches including intervention modelling and developing a shared language with technology developers can support digital health intervention development. Unanswered questions remain around how to ensure optimal benefit to users of digital technologies when used in the delivery of palliative care, how to learn from deviation, and how to understand what is influencing interaction and use.

Abstract number: PS06
Abstract type: Parallel Session

"I went to the beach without leaving my bed" -- virtual reality for symptom management in advanced illness: current evidence and applications

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Aims: Virtual reality (VR) is a rapidly developing, multisensory technology that allows users to immerse themselves into a three-dimensional

experience. Palliative care clinicians and researchers are beginning to leverage VR to improve patient illness experience. This session will introduce VR technology, provide an overview of current applications, and postulate future directions.
Methods: Clinical literature review with specific technology case applications and discussion
Results: While the existent clinical research base has long focused on VR use in procedure-related pain, newer applications target chronic pain and other disease-related symptoms of interest to palliative clinicians. Additional relevant applications emphasize individualized experiences, such as virtual travel or recreation. As VR technology rapidly evolves to deeper levels of immersive experience and affordable technology hardware including smartphones, palliative care stakeholders are increasingly incentivized to employ these novel non-pharmacologic interventions.
Conclusion: Evolving VR technologies offer opportunities to explore new non-pharmacologic strategies to improve health-related quality of life in advanced illness.

PS07 (A) Peer Support in Palliative Care: How to Leverage its Potential?

Abstract number: PS07
Abstract type: Parallel Session

Face-to-face peer support groups in palliative care: findings from the first largescale SMART study

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Aims: Patients with advanced cancer and their relatives spend most of their time outside the healthcare system. They have to self-manage all aspects of living with the disease. In palliative care, peer support may have unexploited potential of support, but it may also be challenging. We aimed to develop and test the feasibility and content of a peer support programme for patients and relatives living with advanced cancer, based on the Chronic Disease Self-Management Programme (CDSMP).
Methods: In the SMART study (acronym for Self-Management programme for persons with Advanced cancer and Relatives Trial) experts groups of patients, family caregivers, healthcare professionals and scientists adapted the content and mode of the CDSMP to the online “Living with cancer” group programme. The programme was piloted and peer-leaders were trained.
Results: Only few topics were replaced or adapted to the target group. Of the twelve participants in the pilot three missed one or two sessions. All themes were recommended to be included in the final programme and participants positively appraised the attendance of patients and relatives in the same group. Participants appraised the programme with the satisfaction score of 8.5 (scale 0-10), and both providing and receiving support from peers in an online group was highly appreciated. Subsequently, 12 patients and relatives were trained to facilitate the process of peer support in online groups. Pilot participants and peer leaders were almost effortless recruited via various social media, and social and professional networks.
Conclusion: In palliative care, peer support in groups for persons living with advanced cancer is promising. It was easy to recruit participants and peer leaders and the mutual support of peers was appreciated.

Abstract number: PS07
Abstract type: Parallel Session

Viral- International online peer support & learning in palliative care

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Aims: In Wales, the Advance & Future Care Planning (AFCP) strategic group oversees the national direction for advance care planning. The aim is to establish a peer-supported campaign to effectively inform people about AFCP. The group includes patient representation and has had a strong focus on promoting person-centred AFCP via new media.
Methods: Several social media campaigns, for instance #TalkCPR, #FutureCarePlanning & #WhatMattersMost, have been led & co-directed by technology-savvy patients & carers. YouTube videos on the complexities of resuscitation & AFCP education have been co-created by patients. Apps, websites, YouTube channels & hashtags were created including https://advancecareplan.org.uk, www.wales/nhs.uk/DNACPR, #TalkCPR & http://talkcpr.com. Patient groups helped write scripts for explanatory videos. A national conference in 2019 further helped to set direction. Resources have been accessed over a million times, including countries like Lesotho.
Results: The online content has had a worldwide reach & highlighted Welsh advance care planning materials. As an example, a patient wrote about the resources on a medical journal site, “Twitter helped me decide that I’m not for resuscitation” in the BMJ ‘What your patient is thinking’ series. The article was downloaded over 10,000 times, with readership breakdown of 61% members of public, 29% practitioners, 8% scientists & 1% journalists.
Conclusion: Our patient & carer representatives have stated that by connecting to others in similar situations, including via social media, they found solace & felt less alone. The discussions between patients, carers & bereaved next-of-kin on Twitter that are associated with our Welsh campaign’s hashtags, have made for sometimes challenging but valuable learning. Peer-support in the online world of social media is real & at present it is uncharted new territory. Moral & ethical challenges on how to recruit into, establish & maintain peer-support structures are discussed.

Abstract number: PS07
Abstract type: Parallel Session

An introduction to peer support: what do we know, what questions remain, and what is the future of peer support?

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Aims: To review 50 years of peer support
Methods: Review of Stanford/Self-Management Resource Center Self-Management Programs
Results: Starting in the 1970s we began developing and evaluating peer led community based psych/educational program for people with arthritis and other chronic diseases. There were several reasons for choosing peers as educators 1) they know the communities they serve and act as models. Modeling helps increase self-efficacy, 2) peers are plentiful and cost efficient, 3) peers are willing to work in communities, 4) peers allow health professionals to work at the top of their skills level.
Early questions were 1) could peers safely and effectively deliver interventions and would peer delivery be acceptable to health professionals. In more than 50 randomized and long term trials we learned that those attending peer led self-management programs improve health status, health behaviors, and self-efficacy while reducing health care costs. Peer led programs can be replicated with fidelity, widely disseminated and are largely acceptable if not embraced by health professionals.
Today over 1000 organizations in 30 countries deliver our programs for those with diabetes and other chronic conditions, cancer survivor, and caregivers. During the Pandemic, the programs continued via virtual platforms and telephone reaching several thousand people many of whom were not reached by in person delivery.
Health care systems have been largely accepting of peer led programs. However, payment systems in most countries have been slow to embrace this model. This is due to the programs been offered largely by community based agencies, outside of the health care system and also the unwillingness to reallocate funds away from traditional health care services.

Conclusion: Just as knowledge alone is not enough to bring about individual behavior change, Knowledge of effectiveness and cost effectiveness is not enough to produce system change.

PS08 (M) Expanding Palliative Care Beyond Health Care Services: Lessons Learned From International Research

Abstract number: PS08
Abstract type: Parallel Session

How Do Specialized Palliative Care Services Engage with the General Public? A Survey from Belgium, Sweden and the UK

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Aims: Public health palliative care is based on the concept that, whilst there are aspects of care that require professional support, death, dying, loss and care are social experiences that require social responses. As such, it gives emphasis to the role of specialist palliative care services (SPCS) in moving beyond their clinical mandate to reach the wider public in relation to raising awareness of and capacity to support death, dying and loss within existing social networks. Such a public health approach is being implemented by SPCS's in several European countries; however, comprehensive documentation and evaluation of the approach is largely lacking.

Methods: An anonymous online cross-sectional survey was sent to SPCSs in Flanders (Belgium) (n50), Sweden (n129) and the UK (n245). The survey collected information on service characteristics, activities with the general public, and attitudes towards the role of SPCSs in engaging with the general public. Data were aggregated by country and differences between countries examined.

Results: Response rate was 84% in Belgium, 70.5% in Sweden and 49.4% in the UK. All countries viewed SPCSs as important partners in palliative care and only a minority reported no current activity. All countries were engaged with a variety of organizations to develop knowledge and skills in the general public. However, there was a substantial country-variation in the degree of engagement, with SPCSs in the UK expanding the focus of the service beyond the clinical mandate, compared to in Belgium and even more so compared to in Sweden.

Conclusion: The findings identify the extent to which palliative care services in the different countries are already working with the general public and in what domains. However, the findings suggest that the extent to which SPCSs view themselves as having a role in mobilising such support depends on the local context, including how healthcare is delivered and funded and cultural understandings of community.

Abstract number: PS08
Abstract type: Parallel Session

Creating Collaborative Community Culture at the End of Life: Insights from an Asset Based Community Development project in Australia

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Aims: The Healthy End of Life Program (HELP) uses evidence-based public health strategies, including health promotion and community development, to create collaborative community cultures aiming to promote and support place-based end-of-life care.

Methods: HELP is the product of a three-phase research and practice enquiry. The first phase examined carers' experiences of home-based dying, the networks that supported them during care, and broader community networks with the potential to extend care. Qualitative and Social Network Analysis (SNA) methods were used to understand and measure changes in community collaboration in two studies. Phase two brought public health strategies to bear on the themes identified in phase one to develop HELP, an sset-based public health palliative care intervention. The third and current phase involves implementing and evaluating this model in different Australian and international contexts.

Results: A major theme emerging in phase one of the enquiry was the reluctance of carers to ask for, or even accept, offers of help from family, friends and community networks despite rich social networks and a need for support while providing end-of-life care at home. Others' willingness to provide support was hindered by uncertainty about what to offer, and concern about infringing on people's privacy. To develop community capacity for providing end-of-life care, these counter-intuitive social norms need to change. SNA of a bounded community network demonstrated an increase in community collaboration between and within formal and informal networks of care.

Conclusion: HELP provides an evidence-based and research-informed public health palliative care intervention strategy and evaluation framework that generates a collaborative community culture to support place-based end-of-life care. However, the social norms of asking, accepting and providing help must be solved at the individual level to produce successful outcomes.

Abstract number: PS08
Abstract type: Parallel Session

Creating Palliative Care Capacity Across Society: Evaluating Compassionate City Programs

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There is increasing recognition that the challenges of health and wellbeing around serious illness, dying and bereavement substantially go beyond the scope of professional healthcare services. After all, the greater part of people's experiences of living with and dying from a serious illness and providing informal care is outside of the context of formal health care. The idea of palliative care as everyone's responsibility is increasingly embraced as a complementary paradigm. One example of such civic responses to the societal challenges around serious illness, death and loss is the concept of the 'compassionate city'.

Compassionate cities are social ecology approaches, based on principles of participation, empowerment, inclusion, respect and dignity, that want to consider serious illness, dying, caregiving and grief as everyone's business.

In Belgium, in the context of a large interuniversity research project, two municipalities have committed to become a compassionate city: one large highly urbanized city (Bruges, >100k inhabitants) and one small moderately urbanized (Herzele, <20k inhabitants). This presentation aims to1)document and evaluate the process of development of the two compassionate cities, 2) present their outputs and preliminary impact, 3) discuss commonalities and differences between the processes of both cities.

In both cities various stakeholders, including local governments, health and wellbeing organisations, workplaces, schools, life-stance organizations and neighbourhoods have partnered in a coalition to work out actions aimed at prevention, harm reduction or intervention around serious illness, death, dying, loss and caregiving. The actions being developed include awareness raising, education, policy development and creation of new or strengthening of existing social networks in cocreation

The insights regarding the process and impact of the two compassionate cities can provide inspiration for other cities to develop 'civic palliative care'.

PS09 (G) Revealing the Current State of Palliative Care for Persons with Persistent Mental Illness in Three High Income Countries

Abstract number: PS09
Abstract type: Parallel Session

The Views and Experiences of People with Mental Illness, and their Carers, on their Palliative Care Needs

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Background and Aims: Research on the specific needs of people with severe mental illness (SMI) in palliative and end of life care is extremely limited and focuses on describing barriers to care from clinician's perspectives. The views of patients with both SMI and incurable physical conditions, and their carers, have not been included in previous research studies.This study, carried out as part of a bigger research project, aimed to amplify the voices of patients and carers and understand their needs to onform clinical practice.
Methods: Eight participants were interviewed using a semi-structured interview format. Five were patients with mental illnesses and incurable physical conditions and three were, or had been, carers of people with mental illness and incurable physical conditions. Interviews were transcribed and a reflexive thematic analysis carried out. A conceptual framework of themes was developed from the interview analysis.
Results: Four overarching themes were developed from the analysis of the data. 1) Stigma and Prejudice – 'See me not my diagnosis' 2) Hesitancy and Avoidance - 'Treading on eggshells' 3) Collaborators in Care – 'the ignored experts' and 4) Connections 'Leaning in, not stepping back'. Each will be discussed and illustrated with participant views.
Conclusions: This study offers novel understanding of the views, experiences and expectations of a group of patients often marginalised and excluded from palliative and end of life care - people with severe mental illness . The themes developed from the interview data offer valuable insights into how access to, and quality of, palliative and end of life care can be improved for people with SMI. The findings are of interest to clinicians, policy makers, patients and carers.
Impact: Clinical staff often struggle to have time to read research papers and attend conferences. A short animation was made to share some of the findings from the study and will be shown as part of the presentation.

Abstract number: PS09
Abstract type: Parallel Session

Palliative Care in the Gaps: Experiences of Palliative Care for Persons with Persistent Mental Illness in the Community

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Aims: Presence of mental illness is strongly associated with poor physical health and inequitable health outcomes. Despite this, those with mental illness receive fewer interventions, have increased morbidity from life-limiting illnesses, experience greater illness severity, and die younger. Symptoms of advancing illness often go unnoticed leading to late presentation, diagnosis, treatment, and delayed or no referral to palliative care. Health inequities are even more pronounced when persons with mental illness also experience structural vulnerability. Structural vulnerability includes economic and social marginalization such as poverty, racialization, and homelessness.
Methods: Secondary thematic analysis drew data from a larger critical ethnographic study of people in need of palliative care who experience structural vulnerability. Transcripts of semi-structured interviews were extracted for participants who self-identified or were identified by providers as also having a mental illness (n=14). Data also included fieldnotes from interactions with healthcare providers, social services, transitional housing workers, and community members across multiple sites.
Results: Themes included absence of attention to mental illness and ambiguity regarding symptoms, symptom etiology, provider role, and treatment. Assessment, crisis prevention, or treatment for mental distress were seldom addressed as part of a palliative approach. Providers lacked system and professional resources to explore the implications of a participants' mental illness in relation to their palliative care needs, regardless of their role. In some cases, a diagnosis of mental illness served as leverage for providers to access services (e.g. housing).
Conclusions: These findings provide researchers and clinicians with valuable information about experiences of persons with mental illness in the palliative phase, and contribute to a body of research to inform recommendations for practice.

Abstract number: PS09
Abstract type: Parallel Session

Palliative care for people diagnosed with mental illness : The New Zealand perspective

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Helen Butler is the Associate Head of Mental Health and Addiction in the School of Nursing at the University of Auckland. She worked as a Registered Nurse for over 25 years and mostly specialised within mental health and specialist palliative care (in NZ and Australia). She is passionate about the issues of equitable healthcare for people with a diagnosis of mental illness and identified in her research that gaping inequities exist. These inequities not only arise from the systems that health professionals work under; it is also the values, attitudes and behaviours from health professionals themselves that impact on the care (or lack of care) that people with a diagnosis of mental illness receive. She is working towards her PhD and exploring more deeply around the inequities of palliative care for people with a diagnosis of mental illness. Helen will present findings from her masters research which expanded understanding of the current gaps and inequities in palliative care affecting persons with persistent mental illness. Emphasis will be on sharing insight into the current state of care with an eye towards recommendations for improvements in health professional practice, policy, and future research from an international perspective.

PS10 (B) (Potential)Pitfalls in Palliative Care Pharmacotherapy

Abstract number: PS10
Abstract type: Parallel Session

Darwin's Legacy - Drug Interactions and Dietary/Herbal Supplements

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The evolution of human drug metabolising capacity began around 400 million years ago as a battle ensued between plants and animals. Through photosynthesis, plants produced primary metabolites such as carbohydrates, proteins, and oils. Plants were unable to prevent predation by insects and animals, and so evolved to develop toxic plant secondary metabolites (PSMs) such as alkaloids, phenolics, and terpenes as a deterrent. Production and storage of PSMs involved numerous plant enzyme and transport proteins, including cytochrome P450 enzymes (CYPs), uridine diphosphate glycosyltransferases (UGTs), and ATP-binding cassette transporters. PSMs evolved to mimic the structures of endogenous mammalian substrates, such as hormones and neurotransmitters, interfering with receptors or enzyme systems (the basis of herbal medicine). Mammals developed analogous CYPs, UGTs, and ABC transporters in order to neutralise noxious PSMs by metabolism and elimination.

By exposure to PSMs over millions of years, humans have phylogenetically inherited the varied enzymes and transport proteins necessary for removing potentially toxic dietary and environmental chemicals. In other words, human drug metabolising enzymes and transport proteins have been influenced by exposure to PSMs, whether by diet or as natural medicines. It is important to note that many PSMs have retained the ability to modulate the activity of human drug metabolising enzymes and transport proteins.

Herbal medicine has been shown to be the most popular complementary and alternative medicine in the UK. It is estimated that up to 20% of cancer patients ($>$300,000 patients) use herbal products for numerous reasons, for example, alleviation of symptoms, to complement chemotherapy, or prevent disease. Given the presence of PSMs and their potential effect on human metabolic pathways, use of these natural remedies, along other plant products (e.g., fruits, vegetables) can give rise to problematic drug interactions.

Abstract number: PS10
Abstract type: Parallel Session

Is Any Jerk a Seizure?

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Background: Epileptic seizures are common in palliative care, especially in the context of brain tumours and brain metastases. Antiepileptic therapy at the end of life has many challenges, starting with the (correct) identification of an epileptic seizure, the duration of therapy and the route of administration in case of dysphagia. The thin evidence base for epilepsy therapy at the end of life is a critical point.

Aim: To present and critically discuss important aspects of pharmacotherapy for epilepsy at the end of life.

Methods: The use of antiepileptic drugs in palliative care is discussed in detail on the basis of typical treatment situations. The emphasis is placed on aspects that are of particular relevance to drug therapy safety. Using antiepileptic therapy as an example, the tension between diagnosis and treatment planning will be examined in the light of scarce evidence.

Conclusion: Drug therapy is an essential tool in palliative care, but also always involves a potential risk for the patient. Awareness regarding potential risks of drug therapy should be raised using examples from everyday clinical practice. Possible management options will be presented.

Abstract number: PS10
Abstract type: Parallel Session

The Cannabis Conundrum

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Reports in the social and printed media about the “astounding” effects of cannabis in treating many different conditions have led to increased public support for using cannabis as a medicine. With the growing support for access to medicinal cannabis in the palliative care setting, patients and carers are now commonly requesting information on cannabis or for it to be prescribed for symptom control. For health care professionals, this raises many questions and issues. With its history of prohibition, legislation and regulations around the prescribing of cannabis are complex, with most countries adopting different mechanisms and restrictions on its access.

Unlike most medicines currently prescribed in the palliative care setting, many cannabis medicines have not undergone the usual regulatory processes before being made available as a medicine. This limits the information available on pharmacokinetics, pharmacodynamics, efficacy, adverse effects and drug interactions. A diverse range of medicinal cannabis formulations, ranging from a few containing a single drug to varying combinations of active ingredients, also exists, complicating selecting the most appropriate formulation and dose to use. The existence of non-pharmaceutical grade cannabis products further complicates the situation. Evidence-based prescribing is challenged by the limited evidence available on the clinical use and efficacy of cannabis medicines in palliative care, while health professionals may not have received sufficient training to assist them in their decision making.

This presentation will discuss the various issues and challenges health professionals face when considering cannabis medicines in the palliative care setting.

PS11 (D) Developing an Evidence Base to Support Advance Care Planning in Dementia

Abstract number: PS11
Abstract type: Parallel Session

Developing Guidance in Addressing the Challenges of Advance Care Planning in Dementia: An EAPC Delphi Study

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Aims: Advance care planning in dementia is often highly complex. Despite increasing research efforts, there is still little evidence how to best engage individuals with dementia and their family caregivers in advance care planning. The multidisciplinary EAPC task force advance care planning in dementia aims to synthesize what is known and to provide guidance based on evidence and on consensus.

Methods: The task force prepares initial guidance based on adaptation of recommendations underpinned by previous Delphi studies on advance care planning for those with capacity (mostly), and on palliative care in dementia (to a limited extent). We expand and update the guidance with literature and input from a small group of experts. This represents the first, qualitative round of a new Delphi study to achieve consensus and highlight any remaining divergence.

Results: Most recommendations for those with capacity have been adapted. From the adaptations, three main and interrelated areas of difference in case of dementia emerged: capacity, family, and engagement (in terms of the active role played in conversations and communication).

Conclusion: Advance care planning in dementia clearly requires specific guidance to support practice, policy and research. We anticipate four or five rounds with a wider panel of experts between fall 2021 and spring 2022 are needed to achieve a consensus on a definition, typology and recommendations. This may also highlight remaining ambiguities around advance care planning in dementia some of which are generic to advance care planning with those with diminished capacity.

Abstract number: PS11
Abstract type: Parallel Session

Implementing Advance Care Planning with Family Caregivers of Nursing Home Residents in Italy

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[2]Città della salute e della Scienza, Turin, Italy

Aims: In Italy knowledge of nursing home staff on ACP is suboptimal. Al though attitudes towards ACP are positive and benefits are clearly recognized, it is practiced rarely for reason of concern of upsetting the patient or their family, or a belief that patients or relatives are not ready for these conversations. Joining the JPND-funded mySupport study provided the opportunity for a structured implementation and evaluation of advance care planning with relatives of nursing home residents with dementia.

Methods: The study employed a case-study approach collecting qualitative and quantitative data extensively in a two nursing homes. It started after the coronavirus outbreaks Nurses were trained to conduct family conferences to discuss ACP with relatives after having received a booklet with information on possible choices related to end-of-life care.

Results: So far several family conferences have been conducted, led by nurses with the participation of home care staff. The conversations lasted longer than expected, were well accepted by relatives and were the occasion for a wider discussion with the family on care provided to patients with advanced dementia. Not all nurses felt able to conduct these conversations.

Conclusions: Advance care planning should occur in a way that upholds the familial and relational aspects of older people's lives that often matter to them the most. It should be common practice in nursing homes and conducted by familiar professionals involved in the care of the person.

Abstract number: PS11
Abstract type: Parallel Session

Engaging in Advance Care Planning Conversations: Lessons Learned from People with Dementia and their Family

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[1]Vrije Universiteit Brussel (VUB), VUB-UGhent End-of-Life Care Research Group, Brussels, Belgium

Aim: Advance care planning (ACP) recommendations are mostly professional based. "Nothing about us, without us" is commonly expressed by people with dementia. We aimed to identify the unique views and preferences of people with dementia and their family regarding ACP, both in a professional and family context.

Methods: A review of reviews, focus groups and interviews with people with young and late onset dementia and family in Belgium, and the European Working Group of People with Dementia, a formal reference group supported by Alzheimer Europe.

Results: Common themes emerging from 19 reviews and 4 research studies involving 22 people with dementia and 46 family, are that people with dementia and their family:

- find ACP important and expect professionals to initiate ACP, but several personal (eg living in-the-moment attitude) and contextual barriers (eg lacking information on prognoses or on ACP; inadequate care options for people with young onset dementia) hinder engaging in ACP in practice
- view ACP as more than a medical process and more than a need to plan the end of life via documentation. ACP should include conversations on what is important to people in their nearer future and should not only focus on medical but also on social care, as well as on future daily life activities
- stress the importance of using strategies to support people's decision-making capacity, which fluctuates and is task specific
- highlight the importance of discussing ACP in a family next to a professional context, as engaging in ACP might emotionally benefit the family when faced with difficult end-of-life decisions. A trusting and safe environment to discuss ACP is emphasized
- highlight the need for a process-oriented approach, and for flexibility and tailoring the approach and timing to the person

Conclusion: In future conceptual and interventional work concerning ACP in dementia, it will be important to take into account these unique perspectives of people with dementia and their family.

PS12 (B) Treatment Decision-Making: Communicating, Informing and Supporting Patient Choice

Abstract number: PS12
Abstract type: Parallel Session

Clinician-Patient Communication and Treatment Decision-Making in Advanced Kidney Disease: Protocol for the OSCAR Study

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Aims: For older people with advanced kidney disease, dialysis has uncertain survival benefits and greatest impact on quality of life. Conservative care can be a beneficial alternative, but rates vary considerably. Differences in how clinicians communicate treatment options influence patients' decision-making.

The Optimising Staff-patient Communication in Advanced Renal disease (OSCAR) study aims to:

1. Understand communication, information provision, and decision-making support in renal units with varying rates of conservative care
2. Identify and describe interactional features of consultations between older people (age 80+/ 65+ with poor performance/ comorbidities) with advanced disease (eGFR <20) and renal clinicians
3. Develop an intervention, incorporating clinician training, to enhance how renal clinicians support patients' decision-making
4. Contribute to the evidence-base on implementing patient-centred decision-making

Methods: Mixed-methods via 4 work packages:

1. Ethnographic observation at 5 UK renal units with differing rate of conservative care; clinician interviews; analysis of patient information resources.
2. Video-record consultations between clinicians and eligible patients (and carers) and use Conversation Analysis to identify trainable elements; patient-/carer- and clinician-reported questionnaire data; patient and carer interviews.

3. Co-production of the intervention with stakeholders, integrating study findings; iterative ‘think aloud’ clinician interviews to refine the intervention.
4. Pilot the intervention in another unit; examine clinician views/experiences and video-record post-training consultations; finalise the intervention.

Results and conclusion: OSCAR will result in an intervention to optimise renal clinician’s communication and support patient-centred treatment decision-making. The intervention will be formalised, evidence-based, fit for purpose, acceptable to stakeholders and (if effective/cost-effective) scalable across renal units.

Abstract number: PS12
Abstract type: Parallel Session

Information-provision in advanced cancer care

van Vliet L.[1]
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Aims: Patients with advanced cancer need information about their treatment aim, possible treatment options and possible side-effects. But providing information is not always without challenges. In this presentation van Vliet will address these challenges and focus on how information might help and harm patients when providing information about treatment aims, options and side-effects in advanced cancer.
Methods: In order to describe how information might help and harm when discussing treatment aims, options and side effects, results from audio-recorded consultations, qualitative interviews and survey-studies will be used.
Results: Discussing the incurability of an illness might be a challenge; being aware of the disease status is important but (temporary) denial can also be beneficial. Discussing the (non)treatment option of aggressive anti-cancer treatment might be a challenge; which remains a sensitive issue. Discussing side effects can be challenging, with variation in (patient) preferences.
Conclusion: Information-provision in advanced cancer is no magic bullet. Clinicians need to balance ethical and moral guidelines for open information with the duty to do no harm.

Abstract number: PS12
Abstract type: Parallel Session

Supporting Treatment Decision-Making in Practice

Loucka M.[1]
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Aims: Research evidence shows that most patients prefer to be informed about their prognosis and that it is important to balance potential treatments with their values. However, delivering serious news and communicating about poor prognosis and end of life care remain challenging for clinicians.
Methods: Building upon the results of available evidence and clinical experience, a set of recommendations for improving clinicians’ communication skills will be introduced.
Results: There are several tools that can be implemented at individual or organizational levels to improve clinicians’ skills in communication about serious news: structured training using role-play exercises; mentoring and feedback; question prompt lists; structured guides for conversations with patients and families; and documentation. Timing of these conversations in the disease trajectory will be also discussed as one of the challenging issues in this area.
Conclusion: Delivering serious news is a challenging, though crucial skill for every clinician. By adopting tools to ensure continuing education and improvement of communication skills, we can ensure that patients and their caregivers will benefit from conversations that are effective, honest and empathetic at the same time.

PS13 (C) Children and Young People: The Hidden Carers

Abstract number: PS13
Abstract type: Parallel Session

Children and young people caring for dying parents in the UK

Marshall S.[1]
[1]King’s College London, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, London, United Kingdom

The session will explore the often invisible caregiving role that children and young people take on when living with parental life-limiting illness. There is mounting evidence showing that young carers experience poorer mental and physical health than their peers, and that this can extend into adulthood. The three international speakers from the UK and the US will explore this issue of young caring from differing international perspectives: firstly, by presenting primary data from UK children caring for a dying parent, secondly the development of a U.S. evidence-based intervention (YCare) targeting children and youth caregivers, providing multidisciplinary care skill building, carer education, and social support for children who are caring for a parent with neurological disease. Thirdly by considering the role of policy in ensuring children and young people in Scotland are identified, have their needs assessed and are well supported.

Abstract number: PS13
Abstract type: Parallel Session

U.S. Caregiving Interventions for Children and Youth Caregivers

Kavanaugh M.S.[1]
[1]University of Wisconsin - Milwaukee, Helen Bader School of Social Welfare, Milwaukee, United States

Aims: This paper presents pilot data from a novel care training skills and support program for children and youth who provide care (young carers). The protocol, *YCare*, includes 4 modules delivered by trained allied health professionals: 1) basic care (transferring and dressing), 2) speech and feeding, 3) assistive devices (communication, BiPAP, and power chair), and 4) young caregiver support. The data presented was tested in a population of youth providing care for persons living with Amyotrophic lateral sclerosis (ALS). Primary study AIMs: 1) Youth participants in the *YCare* protocol will show improved self-efficacy in care tasks, and 2) Youth will show improvement in social support.
Methods: The study utilized pre/post surveys to assess change in caregiver self-efficacy and social support, and included qualitative exploration about the training.
Results: A total of 19 youth, between the ages of 9-19 participated in a day long *YC*are program. The majority of participants were male ($n = 13$), providing care for male care recipients with ALS. Participants had little training prior to *YC*are, yet were involved in care tasks ranging from toileting to bathing, to feeding and managing assistive devices. Participants increased their confidence scores across assistive devices and basic care skills. Additionally, qualitative exploration revealed “like” peers, hands-on training, and working directly with allied health professionals as vital parts of the *YC*are model.
Conclusion: Young carers lack skills training and support, despite engagement in often intensive care. This pilot data provides preliminary evidence of the efficacy of a *YC*are, a novel skills program for young carers. Results highlight the value in sharing the experience with “like” peers, who are also involved in care, as well as receiving training from

professionals who allowed them to try out and experience the tasks. These data have clear implications for young carers across disorders.

Abstract number: PS13
Abstract type: Parallel Session

Protecting Mental Health by Identifying Children and their Needs When an Adult Is Ill

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Healthcare consultations with adults are rightly focused on the needs and priorities of the presenting patient. Children are rarely brought to appointments, exacerbating the invisibility of a patient's wider family network and particularly relationships with children. This has become acutely evident during the COVID-19 pandemic due to visiting restrictions.

Parental illness can have serious implications for children's psychological wellbeing and bring additional caring responsibilities for young people. It is therefore critical for the children of adult patients to be identified by healthcare staff so that they can be offered appropriate support. Moreover, effective communication with children about an important adult's illness has long term benefits for their psychological wellbeing and family functioning. Conversely, an absence of developmentally appropriate information can increase the risk of emotional and behavioural problems, including depression and anxiety. Global research has shown that children want and need to know when someone they love is ill. This information enables children to make sense of their observed reality and advocate for their own needs as carers.

Healthcare professionals may feel uncertain about their role in identifying children of adult patients and how to raise these sensitive conversations. Medical staff report wanting specific guidance and training resources about navigating this aspect of care; these are not one-off conversations and need to be regularly reviewed, particularly in the context of changing care needs of parents and children's evolving understanding of illness and death during childhood.

PS14 (E) Rebalancing Death and Dying: The Lancet Commission on the Value of Death

Abstract number: PS14
Abstract type: Parallel Session

Death, medicine, immortality, and climate change

Smith R.[1]
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Conventional medical research is not explicitly pursuing immortality, but it does seek to "cure" all diseases, leaving open the question of how we might eventually die. Conventional medical research does, however, seek to extend life, and global health life expectancy has increased, although "healthy life expectancy" has not increased as rapidly as life expectancy, meaning the period spent in ill health at the end of life has increased.

Although conventional medical research does not explicitly pursue immortality, there are many scientists working in generously funded organisations—particularly on the West Coast of the US—who are explicitly pursuing dramatic life extension and even immortality. They are using several methods, which my talk will discuss.

The social critic Ivan Illich argued in the 1970s that medicine had made an implicit but false promise of conquering pain, suffering, disease, and even death and in doing so had replaced traditional cultural responses to those human issues so destroying meaning and increasing suffering. I will discuss whether these views have validity in 2021.

Abstract number: PS14
Abstract type: Parallel Session

The Complex Death System: Mapping People, Pathways, and Structural Determinants of End-of-Life Care

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Background: Dying and death are universally experienced, and have myriad experiential, relational, structural, and existential aspects that are relevant to the design of end-of-life care. Systems science can be applied to examine the complexity of these aspects. The objective of this paper is to use systems thinking to develop a dynamic and non-linear framework of death as it intersects with the health system.

Methods: Systematic reviews which identify factors important to the quality of end-of-life care by patients, caregivers, providers, society, and the health system were analyzed. Using the results of this analysis along with key themes from discussions and brainstorming sessions of The Lancet Commission on the Value of Death, a causal loop diagram/map of the death system was developed to illustrate the death trajectory based on patient, and family and informal caregiver perspectives.

Results: The death system map is anchored by two key events – impending death, which arises from knowledge or sense of death, and death itself. The map tracks multiple factors – actions, processes, experiences, and outcomes – and their interactions related to these events. Subsystems – human, health, sociocultural, political, legal, and economic – and related fault lines are also identified. The non-linear and dynamic nature of the death system is depicted, illustrating reinforcing and balancing feedback loops that demonstrate how death is devalued, revalued, prepared and cared for, faced, tamed, and socially experienced, as well as how impending death or its occurrence impacts quality of life of patients and families. Together, these capture the people impacted by, pathways influencing, and structural components determining the state of end-of-life care.

Conclusion: The death system map serves as an illustration of the complexity of dying and death. It provides a conceptual and action-based framework to generate responses to issues and barriers experienced at the end-of-life.

Abstract number: PS14
Abstract type: Parallel Session

Rebalancing Death and Dying: The Lancet Commission on the Value of Death

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The proposition of the Lancet Commission on the Value of Death is that our relationship with death and dying has become unbalanced and we advocate a rebalancing. Death and dying have become unbalanced as they moved from the context of family, community, culture and relationships to sit within the health care system. Healthcare has a role to play in the care of the dying, but interventions at end of life are often excessive, and exclude other contributions, increasing suffering and consuming resources that cannot be used to meet other needs.

Yet at the same the relationship with death and dying in low- and middle-income countries is unbalanced with the rich receiving excessive care, while the poor, the majority, receive little or no attention or relief of suffering and have no access to opioids, as the *Lancet Commission on*

Global Access to Palliative Care and Pain Relief showed. Excessive treatment for the rich and inadequate or absent care for the poor is a paradox and a failing of global health and solidarity.

The Commission recognises that rebalancing death and dying will depend on changes across "death systems," the many inter-related social, cultural, economic, religious and political factors that determine how death, dying, and bereavement are understood, experienced and managed.

We intend our report to inspire a collective vision for the future. Our recommendations outline the next steps we would urge policy makers, health and social care systems, civil society and communities to take.

PS15 (Q) Researcher Award Session

Abstract number: PS15
Abstract type: Parallel Session

English Palliative and End of Life Care: Several Observations from an Anthropologist

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Milton Keynes, United Kingdom

As an anthropologist who studies palliative and end of life care, my research often sits at the margins of different disciplines. It is therefore with great honour that I receive this award. When I had the opportunity to do a PhD about end of life care in England, I wanted to use my anthropological skills and thinking to understand a core policy concept at the time – 'choice' – that was framed most prominently through advance care planning. I sought to understand what it was, how it was being done and how people engaged with it, and how this shapes care, living and dying. I examined policy discourse, observed care practices in range of settings, and spent a lot of time with people who were potentially in their last year of life. Anthropological attention to palliative and end of life care can raise questions and provocations for the field, such as shifting the focus from choice as an individual act and object to one of interaction, or questioning how it fits with concepts of 'good death'. Using the insights from my research, I've made several films with the Open University and with BBC Ideas to raise awareness of advance care planning whilst also showcasing the people encounter.

Abstract number: PS15
Abstract type: Parallel Session

Improving Patient and Family Care Using Patient Centred Outcome Measures - From Development to Implementation into Practice

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Measurement is an essential element of evidence based medicine and provides the necessary information clinicians require to make decisions in patient management. Patient centred outcome measures are a type of questionnaire which is filled by the patient about themselves or by someone familiar with their disease trajectory and fills the measure in relation to the patient. These questionnaires allow for specific measurements of palliative needs in all dimensions of the person with advanced disease, including concerns and distressful issues. It is therefore vital that these are accurate in terms of language and cultural adaptation, psychometrically tested and valid for the population of interest. Clinical training on the use of these measures, specifically on how, when, why and which questionnaire to use alongside proper, timely feedback of results, make patient centred outcome measures powerful tools to quickly make a holistic assessment and act upon the priority areas. Additionally, these measures can benefit communication pathways of all involved in patient care by creating a common language and assist the development of a therapeutic plan. Implementing these measures in clinical practice inevitably demands changes to daily routines and there will always be an adjustment period with trial and error, but once these are embedded in routine and results start being used at different levels, the quality of care can be measured and improved upon. Data collected can be used for individual patient care in real time and when aggregated at service/healthcare professional level allows for audits and cost-effectiveness and economic studies. This will provide vital information for policy makers to make informed decisions on how best to use available resources to provide the best care for people with advanced disease and their families.

PS16 (B) Opioids for Chronic Breathlessness - Practical Evidence-Based Prescribing

Abstract number: PS16
Abstract type: Parallel Session

What about Other Opioids: What Do We Know, What Don't We Know?

Johnson M.[1]
[1]University of Hull, Wolfson Palliative Care Research Centre, Hull, United Kingdom

Aims: This talk presents the current evidence relating to the use of other opioids for breathlessness.

Methods: Summary of current published evidence.

Results: There are promising preliminary data for dihydrocodeine in people with COPD. In a cross over randomised controlled trial (RCT), participants received 15mg dihydrocodeine or placebo up to three times daily about half an hour prior to physical exertion. Breathlessness improved and exercise endurance increased when the participants were taking dihydrocodeine. An N=1 RCT trial testing hydromorphone (nebulised, or systemic) or placebo for "as needed" episodes of breathlessness in opioid tolerant patients with cancer. There was no difference in breathlessness at the primary endpoint or change over time. Two trials of oxycodone failed to show any benefit for breathlessness over placebo in any outcome measure used. One was a crossover trial in people with heart failure, and another, a larger parallel group trial.

There is growing phase 2 evidence for the transmucosal fentanyls, mainly in opioid tolerant cancer patients for "prophylactic" use (i.e. in advance of physical exertion). Trials showed greater reduction in breathlessness in the fentanyl arm than placebo, and increased exercise endurance with fentanyl compared with none in the placebo arm. Only one feasibility study tested buccal fentanyl *vs* oral morphine for "as needed" for episodic breathlessness, but only 6 participants were evaluable. Although a shorter time to meaningful relief was noted for buccal fentanyl, but the recovery time was only quicker in the first 5 minutes, making this probably unrelated to serum drug levels. Concerns around use in opioid naïve patients and the potential for addiction and misuse of the submucosal fentanyls need to be addressed.

Conclusion: The promising findings for "prophylactic" use need to be tested for effectiveness and safety in larger trials and are not currently recommended.

Abstract number: PS16
Abstract type: Parallel Session

Are Opioids Safe in Chronic Breathlessness?

Janssen D.[1,2]
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Aim: Since many years, opioids are seen as the cornerstone of pharmalogical palliative treatment of breathlessness. However, clinicians are often reluctant to prescribe opioids to patients with chronic lung diseases because of fear of possible averse effects and fear of respiratory depression. The aim of this presentaion is to explore whether opioids for breathlessness are safe for patients with chronic lung diseases.
Methods: This talk will provide an overview of studies exploring safety of opioids for chronic breathlessness. Included studies are: observational cohort studies, randomized-controlled trials, and systematic reviews.
Results: Opioids ($\leqslant$30 mg oral morphine equivalents a day) are not associated with increased mortality or increased admissions in patients with COPD using longterm oxygen therapy. There is no evidence of significant or clinically relevant respiratory adverse effects of opioids for chronic breathlessness. The most frequently reported adverse effects are drowsiness, nausea and vomiting, and constipation, which are usually mild. Longterm studies are lacking.
Conclusion: Low-dose opioids for chronic breathlessness seem to be safe for patients with chronic lung diseases. Future longterm studies are needed.

Abstract number: PS16
Abstract type: Parallel Session

Does Morphine Help? Evidence for Effectiveness, Dose and Preparations

Currow D.[1]
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Aim: The aim is to explore the current evidence for the use of opioids in the symptomatic reduction of breathlessness.
Methods: This talk reviews the current evidence that is available to describe the community burden of chronic breathlessness (including its invisibility as people reduce their activities to avoid acute-on-chronic breathlessness), the impact on quality of life in physical and mental domains, the fact that self-care is the last of the major drivers of quality of life to be impaired by chronic breathlessness. The talk also reflects on the measurement of chronic breathlessness and the tools that we should use in order to understand the symptom.
Systematic reviews brought together, augmented by double blind, placebo-controlled studies that were not available at the time that the systematic reviews / meta-analyses were undertaken. Safety is also explored.
Results: Meta-analyses established that there is a net benefit for many patients, particularly with chronic obstructive pulmonary disease, with the use of regular, low-dose, sustained release morphine (10mg/24 hours-30mg/24 hours). Approximately two out of three people started on morphine with severe chronic breathlessness will derive symptomatic benefit. Ten mg per 24 hours is the suggested starting dose. Titration should occur slowly as the pharmacodynamics effects continue to accrue over several days once an effective dose is established.
Safety has been reviewed in a systematic review/meta analysis reiterating that when morphine is used this way there appears to be no adverse effect on respiratory rate with no cases of respiratory depression.
There does not appear to be a class effect across all opioids. This needs further exploration.
Conclusion: Regular, low-dose, sustained release morphine can safely and effectively reduce *worst breathlessness* for many people with chronic breathlessness.

PS17 (D) Exploring New Dimensions in Dementia Palliative Care: Making Research Work in Practice

Abstract number: PS17
Abstract type: Parallel Session

Providing a Firm Base: A System-Based Logic Model of Integrated Palliative Dementia (the EMBED-Care Programme)

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Aim: Dementia is the most rapidly rising cause of health-related suffering. To meet growing need requires new models of palliative care, delivered by generalist staff via mainstream services, where people live and receive care. The EMBED-Care Programme is delivering a model of integrated palliative dementia care. The model is underpinned by a system-based logic model detailing an Essential Package of Palliative Dementia Care. This session explores how a logic model could maximise the construction and implementation of integrated palliative care delivery.
Methods: Using the Knowledge to Action Framework to generate and translate knowledge into clinical care, we focus on knowledge creation to construct a system-based logic model detailing our essential package. We used meta-review of systematic reviews to synthesise service level interventions to promote quality of life for people with dementia. Data analysis used an analysis framework from international clinical guidance to identify the essential components, and then refined with service users.
Results: Synthesis of evidence from 23 systematic reviews with analysis through a palliative care 'lens'. Findings generated a logic model of the Essential Package of Palliative Dementia Care, detailing the intervention theory of person-centred care, and the components both well understood, like symptom management, and areas of uncertainty, notably the timing and duration of palliative care, and implementation. Service user perspectives identified priorities for care delivery.
Conclusion: We demonstrate the integration of knowledge between dementia care and palliative care to construct an Essential Package of Palliative Dementia Care. Using a logic model ensured robust underpinning for palliative care delivery by building conceptual understanding from across specialities. This identified opportunities for integration and areas of uncertainty pursued in the EMBED-Care programme to generate knowledge to transform care.

Abstract number: PS17
Abstract type: Parallel Session

The Reality: Understanding why in Practice, Interventions don't Work as Expected

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Aims: Optimal intervention and research design informs practice or future research. Research generally navigates new avenues and must also maximize possibilities to explain why an intervention would have "no effect." For example, because intervention effects fail to generalize without adaptation to different context. The aim of this contribution is to consider design that increases understanding from an initial stage in which you identify expectations of interventions that could improve practice and decide where you would like a trial to be on a pragmatic-explanatory continuum and to a stage of post-implementation adaptations.
Methods: Illustration of tools that support study design, along with examples of interventions in nursing home settings that did not work as expected.

Results: Expectations and therefore hypotheses depend on what is already known and what we actually want to achieve with the research. For example, if developers of an intervention have demonstrated effectiveness, do we, with a more pragmatic approach, expect a diluted effect, or a similar effect when adapted to context? Increased focus or increased observations-often part of palliative interventions-in and of itself may benefit a control group so we need to clarify any additional mechanisms. Therefore, theory on how the intervention may or may not work is essential and theories or frameworks should guide collection of data to evaluate the process of implementation. Anticipation of "weak points" or ingredients not supported by evidence should trigger targeted data collection around those points, to inform post-implementation adaptations.
Conclusion: within boundaries of established research practice, design and implementation to improve practice is still a highly creative process. It requires pro-active consideration of how interventions may or may not work and what adaptations and data to evaluate the implementation may be needed to get the most out of the research.

Abstract number: PS17
Abstract type: Parallel Session

Learning from trials: LIVE@Home.path, an RCT of care coordination for people with dementia

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Dementia is not an unavoidable consequence of aging, but for most nursing home patients and home dwelling people with dementia (PwD) a result of complex chronic conditions. Only 5% of PwD do not have multimorbidity (a combination of e.g., hypertension, diabetes, stroke, depression, and/or pain). Lack of advance care planning, polypharmacy, and psychological and behavioural disturbances (BPSD) require multidisciplinary collaboration, implementation of research results, and focus on digital phenotyping and smart housing. The strengths and limitations of several controlled clinical trials (PAIN.BPSD; DEP.PAIN.DEM; COSMOS) will be presented to argue for the content and method of the stepped-wedged LIVE@Home.Path trial, in which a skilled coordinator is responsible for the implementation of a complex intervention for home dwelling PwD, and their informal and formal caregivers. Family burden and costs are considerable in these settings and in future, sustainable solutions must be developed to enable older adults to stay safe and longer at home, and even die there, if wanted. In this respect, research is necessary to identify and implement best practice. However, the methodology and interpretation of the results often hamper by lack of blinding, and the Hawthorne or Dunning Krüger effect. Further, during SARS-COVID-19, our research activities were impeded to safeguard the study participants. To investigate the consequences of the pandemic for home dwelling PwD, we nested the PAN.DEM study (Pandemic in Dementia) into the ongoing LIVE study and describe the change caregiver burden, BPSD, and the use of technology during the pandemic.

PS18 (F) Ethical Decision Making at the End-Of-Life

Abstract number: PS18
Abstract type: Parallel Session

Nudging and Palliative Paternalism

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The ethical debate about the decision-making process has been recently enriched with a theory called "nudging", defined as *"any aspect of the choice architecture that alters people's behavior in a predictable way, without forbidding any options or significantly changing their economic incentives".*
The techniques of nudging rest on two key concepts known as the 'architecture of choices' and 'libertarian paternalism'. Some researchers argue that patients may not know how to make a choice: in this case providing nudges as a form of 'best interest standard' could be an ethically helpful element in the shared decision-making process.
We organized a Focus Group to explore the attitudes of the professionals working at Reggio Emilia P.C. Unit and Psycho-Oncology Service regarding the potential use of nudging techniques in palliative care.
The analysis of the F.G. results revealed two main categories:

1. Translating nudging in the palliative care setting

Nudging was defined as a "*misleading*" and "*very dangerous*" concept, even if it was described as "*rather appealing*", as it allows the "*preservation of a form of benevolent paternalism"*, which can be reassuring for the healthcare provider, but they also admitted that "*in daily clinical practice, it is difficult not to do it*"

2. The quest for neutrality.

Neutrality is a concept that participants "*can work towards"*: this leads them to stay in a "*neutral space*".
In the decision-making process during the end-of-life phase of an illness, the boundary between the use of nudging techniques and respect for the patient's autonomy is often blurred. Nudging techniques, if used arbitrarily in conversations regarding end-of-life care choices, can present critical aspects and significant risks. In the palliative care setting, the risk of descending a 'slippery slope' towards the forms of traditional paternalism, often associated with these techniques, can be reduced by exercising the principles of *relational autonomy.*

Abstract number: PS18
Abstract type: Parallel Session

Autonomy: A Perspective from the Ethics of Care

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Aims: Ethics can help caregiving and medical care in several ways, but this assumption has to be demonstrated through the empirical and systematic research activity on the ethical issues arising in the relationship of care. In this presentation, I consider individuals - patients, health care professionals, caregivers - as relational and communicative beings needed of a professional ethical framework based on two key concepts: relational autonomy and vulnerability. Thus, this presentation aims to (a) describes the ethics of care and the concept of relational autonomy, and (b) illustrates the practical implications of the ethics of care in the decision-making process and the Palliative care setting.
Methods: Ethics of care will be presented and discussed as an alternative moral framework useful in medical ethics; then, the practical implications of the ethics of care will be shown.
Results: First of all, relational autonomy seeks to consider the influence on individual opportunities that interdependence and subjective vulnerability have. Dignity, respect, vulnerability and care are key concepts for the definition of relational autonomy. Second, healthcare professionals should be able to help patients translate values and preferences into concrete decisions. Lastly, the ethics of care can be empirically investigated, for example, discovering how caregivers in palliative care perceive moral questions and solve them in the care relationship.
Conclusions: The ethics of care offers criteria that integrate those of classical ethics, and in so doing, it can account for the complexity of the relationship between healthcare providers, patients, and their close

ones; these criteria can also show alternative ways of working out the moral problems we typically face in caring for patients at the end of life. More research is needed to demonstrate how those ethical skills have to be developed systematically and if they impact the quality of care and the quality of life.

Abstract number: PS18
Abstract type: Parallel Session

Personal Autonomy and End-Of-Life Decision Making

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This presentation will explore our understanding of autonomy in treatment decision-making at the end of life. We will acknowledge the traditional focus of autonomy as individual freedom and self-determination towards the view that autonomy needs to be contextualised to match the lived situation. Autonomy must be understood through relationships or social interdependence. Resting on a revised view of autonomy we will identify primary directions towards improving treatment decision making at the end of life.

PS19 (B) Sedation at the End-Of-Life Outside Specialist Palliative Care – International Perspectives

Abstract number: PS19
Abstract type: Parallel Session

Use of Sedatives and Sedation at the End of Life Outside Specialist Palliative Care in Germany

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Aims: This project aimed 1) to assess the use of different types of sedation within the last week of life in selected German hospital (H) departments and nursing homes (NH), based on objective criteria, and 2) to explore associated challenges and possible measures of support, as perceived by non- SPC healthcare professionals.
Methods: In four NH and five H departments: 1) Two multicentre retrospective cohort studies, using medical records, of decedents 1/2015-12/2017. Analysis of sedatives recommended in guidelines for "palliative sedation", using objective criteria for "continuous effect" and "at least moderately sedating" doses. 2) Semi-structured qualitative interviews with physicians and nurses.
Results: 1) 260/517 (50%, H) and 46/512 (9%, NH) of decedents received a sedative with "continuous effect" during the last week of life, 53/517 (10%, H) and 11/512 (2%, NH) in "at least moderately sedating" doses. For about a third in both settings, no indication was noted. The term "sedation" was documented for 20/260 (8%, H) and 0/512 (0%, NH). Use of sedatives was significantly associated with institution in both settings (H and NH). 2) Percieved challenges and supportive measures related to three levels of the care situation: *individual*, *interaction with others* and *work environment*. The main challenge was finding the adequate timing and dose. Other challenges on all levels, e.g. disagreements regarding indication or legal uncertainties, were strongly associated with this major challenge. Major supportive measures were education and training, joint decision-making within the team and regular discussion with the patient and family. On the level *work environment*, no implemented measures, but wishes for change were identified.
Conclusion: The observed differences between institutions, deviations from recommended practice and perceived challenges warrant development of additional context-specific support measures for sedation outside SPC.
Funding: BMBF, 01GY1712 (SedEol)

Abstract number: PS19
Abstract type: Parallel Session

Challenges in the practice of palliative sedation outside specialist palliative care: data from an international questionnaire survey and in-depth interviews in the Netherlands

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Aim: The frequency of applying continuous deep sedation in the last stage of patients' life seems to be increasing. It can be questioned whether it is or should be a last resort practice to alleviate unbearable suffering and to what extent this practice can always be clearly distinguished from other practices in care at the end of life.
Methods: An analysis and appreciation of data from a series of Dutch surveys on end-of-life decision making practices, an international questionnaire study among palliative care physicians, and interview studies on experiences and perspectives of different healthcare professionals in the Netherlands.
Results: The use of continuous deep sedation in the Netherlands seems to have been increasing in all patient subgroups, but particularly among dying patients who are attended by general practitioners, patients older than 80 and patients with cancer. In the international questionnaire study, many palliative care physicians were found to consider continuous deep sedation acceptable for the relief of physical and psycho-existential suffering in the last days of life. Opinions varied substantially for patients with a longer life expectancy and regarding routine withdrawal of artificial hydration. In-depth interviews with Dutch healthcare professionals showed that the interpretation of unbearable refractory suffering may have broadened over the years.
Conclusion: The practice of continuous deep sedation is evolving and requires ongoing debate.This may be especially relevant in non-specialized palliative care

Abstract number: PS19
Abstract type: Parallel Session

Palliative Sedation in Flemish Nursing Homes: Reported Complexities and the Development of a Setting-Specific Practice Protocol

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Aims: This project identified complexities inherent the decision making and performance of continuous sedation until death in Flemish nursing homes as experienced by health care professionals. From a.o. these insights, we aimed to develop a protocol to improve the quality of the practice in nursing home settings.
Methods: To map complexities, ten focus groups were held with 71 health care professionals including 16 palliative care physicians, 42 general practitioners, and 13 nursing home staff. The development of the practice protocol was based on the MRC Framework and also made use of the findings of a systematic review of existing improvement initiatives. The protocol was refined through 10 expert panels with 70 health care professionals.

Results: Perceived complexities concerned factors prior to and during sedation and were classified into three types: (a) personal barriers related to knowledge and skills about a.o. conceptual ambiguity and when and how it should be applied; (b) relational barriers concerning communication and collaboration between health care professionals and with family; (c) organizational barriers specific to nursing homes where e.g. an on-site physician is lacking or the recommended medication is not always available.

The protocol encompassed 7 sequential steps focused on clarification of the medical and social situation, communication with all care providers involved and with the resident and/or relatives, the organization of care, the actual performance of continuous sedation, and the supporting of relatives and care providers during and after the procedure.

Conclusion: This project succeeded in developing a practice protocol for continuous sedation until death adapted to the specific context of nursing homes, where multidimensional challenges for sound decision making about and performance exist. Future research should focus on developing effective implementation strategies and on thoroughly evaluating its effectiveness.

PS20 (C) Strategies to Improve the Psychosocial Well-Being of Family Carers: How International Collaborations Make a Difference

Abstract number: PS20
Abstract type: Parallel Session

Evidence Synthesis of Factors Affecting Family Carers' Psychological Wellbeing

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Background: Informal carers provide crucial support for patients at the end of life (EOL), but suffer considerable impact on their own psychological health. Synthesis of the expansive evidence on factors affecting carer psychological morbidity to inform remedial initiatives and interventions is urgently needed.

Aims: To help reduce psychological morbidity among EOL carers through: (1) evidence-synthesis of factors affecting carer psychological morbidity during end of life care; (2) translation of synthesised findings into accessible, tailored information for key stakeholders able to influence change (carer organisations, practitioners, commissioners, and policy makers).

Methods: A structured and comprehensive evidence synthesis of quantitative and qualitative literature (2009-2019) was undertaken, informed by a carer Review Advisory Panel (RAP), to confirm the validity, relevance and accessibility of findings to carers.

Results: Findings from 64 observational studies, 33 qualitative studies and 13 intervention studies identified seven overarching factors affecting carers' mental health: patient condition, impact of caring responsibilities (e.g. workload, life changes), quality of relationships, finances, carers' own internal processes (e.g. mastery, self-efficacy, coping strategies), formal/informal support and contextual factors (e.g. age, gender). Based on the evidence synthesis, a set of recommendations for change were developed by the carer RAP. Wider stakeholder consultation will provide information on the relevance of evidence to key actors who can act on findings.

Conclusion: Providing the first comprehensive evidence synthesis of factors affecting the psychological morbidity of EOL carers will inform the development of future initiatives and interventions to improve the mental health of EOL carers and lead to better targeting of carers at risk of poor mental health.

Abstract number: PS20
Abstract type: Parallel Session

Supporting Family Carer Decision-Making in Palliative Dementia Care

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Best interest decision-making on goals of care at the end of life is complex and can become a significant burden for both family carers and health care providers. This presentation will review the 'Family Carer Decision Support' intervention designed to inform family carers on end-of-life care options for a person living with advanced dementia. An overview on the features of the intervention and its present implementation in six countries will be offered.

Abstract number: PS20
Abstract type: Parallel Session

Key Considerations When Selecting Family Carer Outcome Measures

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It has been said that one cannot change what one cannot measure. This claim resonates for researchers interested in optimizing the skills and outcomes of family carers of patients with serious illness. Measurement aims to ascertain the quantity or magnitude of behaviors, events, and other phenomena. In this session, we address five key measurement considerations in family carer palliative care research. This includes: 1) what instruments best operationalize concepts in one's research question and aims; 2) how to link instruments to a study's larger theoretical framework; 3) how to select instruments appropriate for the carer population; 4) knowing which demographics on carers to collect; and 5) what good resources are to identify valid and reliable instruments for one's study. Stemming from these five considerations, we describe how researchers should choose instruments that operationalize specifically articulated carer constructs in the research aims; identify a theoretical framework that contains all the concepts one purports to measure for their study; choose validated and reliable instruments that have been ideally been used by others in a similar area; collect demographic information that allows one to make comparisons to other work; and utilize established instrument databases and expert guidance to hep find optimal instruments.

Paediatric Palliative Care - Transitioning Children with Palliative Care Needs Between Settings and Phases

Abstract number: PPC
Abstract type: PPC

From hospital to home or hospice care

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Background: Death is an unwanted companion in families with terminally ill children. Nevertheless, many families prefer home death if optimal support is available.

In Denmark (5 million inhabitants) one hospital-based specialised paediatric palliative care team (SPPCT) exists in each of five regions providing hospital and home care.

In Central Denmark Region the SPPCT supports home care nurses (HCNs) and GPs to take care of dying children at home. When children approach death SPPCT arranges presentation meetings with HCNs. Subsequently, SPPCT arranges a meeting in the child's home and also invites the GP. Telephone support and planned follow-up visits by SPPCT is provided throughout the trajectory.

Aim of this oral presentation is to describe and evaluate this method of cooperation.

Methods: Two types of evaluation were done:

A. Place-of-death among deceased children in SPPCT care in the period 2016 - 2021 was calculated
B. A questionnaire to HCNs participating in terminal care of 14 children was developed evaluating the support model

Results:

A. Of the 100 children affiliated to the SPPCT in the study-period 45 children have died (58% from cancer). Only 18 children (40 %) died at hospital and one at hospice
B. Of the 14 children 5 (36%) died at hospital. 20 questionnaires were returned.HCNs agreed/highly agreed that presentation-meetings made them better prepared (78.9%), better at dealing with emotions (73.7%) and better at cooperating (70.6%). 69.2% felt it helped coping with parents' pressure.

They requested clear agreements concerning responsibilities and treatment level. Prerequisites to optimal trajectories were back-up from SPPCT and 24/7 back-up from paediatric wards.

Conclusion: Proportion of hospital deaths in the period was low. The support model was evaluated positively, empowering HCNs to perform palliative care for children concerning knowledge, cooperation and emotions. Clear agreements and back-up were prerequisites for good trajectories.

Abstract number: PPC
Abstract type: PPC

From NICU to Home Care

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Within the context of neonatal palliative care, there are 3 main groups of infant who transition home: (1) Those who are actively dying, including where ventilation will be withdrawn in the home; (2) Infants with a clinical condition that will deteriorate, but who may be relatively stable or will gradually change and (3) Those with an underlying condition that increases vulnerability to life-threatening deteriorations.

When planning discharge, many tasks are common to all 3 groups: equipment and feeding requirements, medication (current and anticipated), and plans for managing a deterioration. Practical issues also need attention: support for the family, training of parents and carers and plans for care around the time of death and after death, including location.

A home extubation should address 3 phases: prior to extubation, around the time of extubation and post extubation. Consider mode of transport home and access to the property, any wishes to be fulfilled once home and a time-scale to extubation. Around the time of extubation, symptom management is important, identifying if anticipatory medications are needed, routes of administration and optimizing the situation for extubation. Post-extubation there must be a plan in place for survival being longer than anticipated, 24/7 professional support and a good symptom management plan.

For infants in groups 2 and 3, on-going management is likely to be a combination of life-prolonging interventions and symptom management. Having robust plans for management of a deterioration will be really important, and these need to be flexible and reviewed regularly. For some, there may be times when full medical intervention, including PICU admission, may be appropriate. At other times, a focus on symptom management and care at home will be the priority.

For all groups, emotional and practical support and shared decision making between the family and professionals are the foundations on which a successful transition is built.

Plenary sessions

Abstract number: PL1
Abstract type: Plenary Session

Is Palliative Care Having an Existential Crisis?

O'Mahony S.[1]
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The phrase "existential crisis" is perhaps too emotive, but palliative care is at a crossroads. My talk will address what I think are the important questions for its future. Given that it cannot possibly take on all death and dying, how can palliative care positively influence the rest of medicine? Why does research on end-of-life care attract so little funding, and why are there so few academic palliative care doctors? Hospices (particularly in the UK) are struggling financially: what should be their role? Should hospices be places providing "de-luxe dying" for the few, or should they be a resource for the many? Is palliative care contributing to the "professionalisation" of dying, and if so, how can we empower individuals, families and communities? Should palliative care concentrate on symptom relief, or should its mission also be spiritual and communitarian?

Abstract number: PL2
Abstract type: Plenary Session

Inclusivity in Palliative Care – Are We as Good as We Think?

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The WHO's strategic priority for Universal Health Coverage identifies palliative care as an essential health service. The goal of access to palliative care for all those who could benefit from it requires policy and health systems to actively promote coverage to all sections of society. The notion of "heard to reach" populations has shifted, with a greater focus on purposeful actions to reach out to communities, offering inclusive services. Dame Cicely Saunders said that "you matter because you are you, and you matter all the days of your life". Person-centred care is core to palliative care. But we must also consider the implications of values-based care, and how our values as clinicians, managers, or researchers influence the evidence we generate, the services we develop and the care we deliver.

Groups that are marginalised in society are likely to have worse health outcomes, and poorer access to care. It is crucial for palliative care to reduce the impact of health inequalities that may persist into death. There is growing evidence of greater need, yet poorer access, among some groups such as LGBT people, people with disabilities, and racial minorities. Minority stress theory explains why experience of discrimination may lead to greater prevalence of some life-limiting illnesses. Structural inequalities also contribute to higher disease prevalence, and to reduced access to preventive and curative health services. The challenge to palliative care is to ensure that our service provision actively seeks to reduce barriers to appropriate, accessible and effective care at the end of life. This plenary will review the available evidence for palliative care need among disadvantaged and socially excluded groups, and highlight evidence for inclusive practice.

Abstract number: PL3
Abstract type: Plenary Session

Meeting the Challenge of Dementia Care in the Future

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Dementia is a global health priority with more than 50 million people worldwide living with dementia in 2020 and the expectation that this number will almost double every 20 years, reaching 82 million in 2030 and 152 million in 2050. Despite advances in the ‘living well with dementia’ culture and person-centred care movement, the dominant narrative and allocation of resources around dementia remains biomedical: focused on the curative and the ‘tragedy’ of loss of cognition, function, and self. Palliative and end-of-life care can be accommodated within both narratives and is increasingly being recognised by academics, policy makers, people with dementia and their advocates as valid and important. In the 2015 World Alzheimer’s report, the third ranked research priority was to identify strategies to anticipate and deliver effective and cost-effective late-life and end-of-life care for people with dementia, including advance care planning. This is further supported by Alzheimer’s Disease International call for action to recognise that people with dementia deserve good quality end-of-life care with respect to their dignity and personal wishes. This message is clear yet barriers to effective palliative care persist:

- under recognition of dementia as a terminal condition
- a trajectory of prolonged but difficult to predict decline
- resource constraints
- expertise of specialist palliative care services to service those with dementia and their families and
- limited evidence of specific clinical management of neuropsychiatric behaviours at the end of life.

Overcoming these and other barriers necessitates a new narrative acknowledging dementia as a terminal illness and development of evidence based models to support high quality palliative care regardless of location.

Abstract number: PL4
Abstract type: Plenary Session

Technology, Innovation, and Artificial Intelligence – A Vision for Palliative Care

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Technology and innovation have been key enablers of delivering better patient care for millennia. Recently, with the availability of substantial data amounts driven by digitalization in medicine, machine learning and artificial intelligence have received a lot of attention in medical research. For instance, the number of annual Pubmed-listed publications containing either the keywords “Machine Learning” or “Artificial Intelligence” is rising since the 1990s. While there were less than 200 articles with these keywords in 1990, this number about doubled to less than 400 in 2000, then increased five-fold to approximately 2200 in 2010, to then see an almost ten-fold (!) increase to a bit more than 21500 articles published in 2020. The interest in these topics is rising in palliative care as well, making it a good idea to de-mystify aspects of associated technologies, and to explain the existing opportunities and challenges to a wider audience. This talk consequently aims at **explaining machine learning and artificial intelligence approaches for digital data analyses**, with a focus on palliative care, to interested EAPC attendees.
The talk will also touch base on future directions of technology innovation to create new biomarkers for the assessment of health status, condition, and prognosis of palliative patients in the last weeks of life. Associated algorithms and systems are currently being researched in a new German Research Foundation funded collaborative research center “empatho-kinaesthetic sensory science” (www.empkins.de) in an interdisciplinary interaction of engineering, ethics, medical, and psychological experts. The systems that are currently being investigated in laboratory environments will enter everyday applicability in a few years. This will open up new possibilities in palliative care, with the aforementioned algorithms and systems hopefully contributing to better understanding of care mechanisms and intervention options.

Abstract number: PL5
Abstract type: Plenary Session

Using Lived Experiences for Re-Designing Care Pathways

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Aims: In oncological treatments with a small survival rate, it can be hard for patients and relatives to maintain control of their care path and to participate in decisions, due to the hectic pace, threat of death and feelings of disempowerment. Although shared decision-making (SDM) attracts a lot of attention worldwide, the focus is often only on the consultation room. The effects of the entire interaction between patients and relatives and the healthcare ecosystem throughout their care path is often neglected. We used a service design perspective on the care path of Locally Advanced Pancreatic Cancer (LAPC) to understand how experiences of patients, their relatives, and professionals over the entire care path accumulate to support their ability to participate in SDM and how service design can improve SDM throughout care paths.
Methods: We used qualitative interviews including design research techniques with patients, relatives, and professionals involved in the diagnosis or treatment of LAPC. The topic list was based on an auto-ethnography written by the plenary session speaker in her role as service design researcher and wife of a patient with LAPC. She is currently also confronted herself with Triple Negative Breast Cancer with metastases.
Results: We found four interconnected service design areas -overview of the process, information provision, teamwork, influence of the physical context- which we integrated in a novel service design approach, called Metro Mapping.
Conclusions: The lived experiences of patients, relatives and professionals, including those of a design researcher who is also caregiver and patient, combined with a service design perspective, shed light on effects

of encounters in the entire care path: i.e. effects on the ability of patients and relatives to maintain control of their care path. The findings serve as a starting point for (re)designing care paths to improve the implementation of SDM in oncology.

Abstract number: PL6
Abstract type: Plenary Session

How Can Palliative Care Navigate the Opioid Crisis

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Which opioid crisis? The world is currently dealing with a number of crises related to opioids. Most of the world, especially low- and middle-income countries, continue to face a crisis of poor opioid access for pain relief, both acute and chronic, for cancer pain and to address palliative care needs. While poor cancer pain management is a current reality for almost 90% of the world's population, it was a common situation in even high-income countries up to the latter half of the 20th Century. This drive to improve pain management focused on cancer pain relief lead by the WHO's Cancer Control Unit, introducing the WHO ladder that cemented the use of opioids for cancer pain. This was extended to acute and chronic pain, especially in the United States, with what in hind sight, has been deemed to be unethical (and illegal) marketing by pharmaceutical companies. In the first decade of the 20th Century, there was increase in opioid associated deaths which was associated with increased opioid prescribing. Causality was hard to attribute as 60% of these deaths involved polypharmacy (alcohol and benzodiazepines) and a third were associated with the prescribing of methadone for pain. Despite the lack of causality, major efforts to decrease the medical prescribing of opioids were undertaken with CDC Guidelines for the management of pain for primary care released in 2016. As opioid prescriptions decreased, opioid associated deaths increased, initially through increased availability and use of illicit heroin imported from Mexico and then from illicit fentanyl (and analogue products) from Mexico and China. Opioid associated deaths have now risen to 90,000 in the US in 2020 (worsened by the COVID epidemic). In the latter half of 2021, the CDC is reconsidering these pain guidelines given significant misinterpretation of the 2016 evidence together with misapplication to patients with cancer and other palliative care who were exempted from those recommendations. The focus on restricting appropriate medical use of opioids has harmed many US residents living with cancer and other diseases, while impacting the rest of the world through example, funding and the influence of the US on global policy, including the World Health Assembly and the Commission of Narcotic Drugs. Palliative Care advocates need to be appropriately informed of true nature of the US situation to ensure it does not detract from improved and appropriate opioid access throughout the world.

P 2 Plenary

Abstract number: B-01
Abstract type: Best Oral

The SILENCE (ScopolamIne butyLbromide givEN prophylactiCally for dEath rattle) Study: A Double-blind Randomized, Placebo-controlled Multicenter Trial

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Background: Death rattle is relatively common among dying patients. Although clinical guidelines recommend anticholinergic drugs to reduce death rattle when non-pharmacological measures fail, evidence regarding their efficacy is lacking. Given that anticholinergics only decrease mucus production, prophylactic administration may be more appropriate.
Aim: To perform a randomised, double-blind, placebo-controlled trial to evaluate the effect of prophylactic scopolamine butylbromide on the occurrence of death rattle.
Methods: Six hospices participated; patients gave advance consent upon admission. Patients in the dying phase were randomly allocated to receive subcutaneous scopolamine butylbromide (20 mg q.i.d.) or placebo. The primary outcome was the occurrence of grade $\geqslant 2$ death rattle as defined by Back measured at two time points at a 4-hour interval. Secondary outcomes included the time between recognizing the dying phase and the onset of death rattle, anticholinergic adverse events, and quality of life (QoL) in the patient's final three days of life.
Results: In total, 1097 patients were admitted to the participating hospices; 635 patients were eligible and 229 gave written informed consent. Eventually, 157 were included in the final intention-to-treat analyses. Death rattle occurred significantly less often in the scopolamine group (13%) compared to the placebo group (27%; p=0·025); an analysis of the time to death rattle yielded a sub-distribution hazard ratio (sHR) of 0·44 (95% CI: 0·20-0·92; p=0·031). Moreover, attending nurses rated patient's QoL as significantly higher in the scopolamine group (median QoL score of 7 versus 6 in the placebo group; p=0·02). An analysis of the time to adverse events yielded no differences between the two groups.
Conclusion: Prophylactic scopolamine butylbromide can safely be used to reduce the risk of death rattle.

P 3 Plenary

Abstract number: L-01
Abstract type: Best Oral

Palliative Day Care in Belgium: Health Economic Analysis Using Population-level Administrative Data

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Background: Palliative day care (PDC) remains a marginal service in Belgium. Yet, palliative day care may represent a meaningful care model, complementary to existing palliative care services. Policymakers require rigorous analysis and evaluation of the service, to determine to what extent the service model should be supported.
Aims: This study aims to evaluate the health economic impact of palliative day care in Belgium, i.e. whether use, and intensity of use are associated with variation in health care consumption and direct medical costs in the last month of life.
Methods: We performed a retrospective matched cohort study using population-level administrative databases linked with health claims data. We compared all decedents between 2010 and 2015 having visited a PDC to a demographically and clinically comparable control group using propensity score matching. Person-level mean cost was calculated for each cost-component.
Results: Using PDC lowers the number of hospital (34% vs 51%; $p<.0001$), ICU and ER admissions (21% vs 30%; p= .002) and decreases the use of medical imaging and invasive ventilation,but increases the number of palliative care unit admissions (39% vs 19%; $p<.0001$) during the last month of life. PDC users did not die at

home more often. PDC use lowers total direct medical costs in the last month of life by €1.025 per capita. Higher costs related to GP contact and palliative care unit (€1.570) use were found, while lower costs related to ICU and ER admissions, specialist contacts, medication and outpatient services. More intensive use of PDC decreased the likelihood of one-day care, specialist contact, home care and palliative home care in the last month, but did not affect overall direct medical costs.

Conclusion: PDC encourages more appropriate care at the end of life. Associated lower direct medical costs coupled with previous findings of significant benefits for and satisfaction of PDC users suggest this model is worthy of government support.

P 4 Plenary

Abstract number: L-03
Abstract type: Best Oral

Demonstrating the Impact of Palliative Care: A Secondary Analysis of Routinely-collected Person-centred Outcomes Data among Hospice Community Patients

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Background: Community-based palliative care support patients in their own homes. Routinely-collected data has rarely been used to show impact of services.

Aims: To estimate prevalence of community patients' symptoms; and measure change in symptom scores at first change of Phase of Illness and end of episode of care.

Methods: We used routinely-collected clinical data between Apr.2019–Dec.2020 in secondary data analysis. We estimated prevalence of symptoms as any moderate/severe/overwhelming score using the Integrated Palliative care Outcome Scale (IPOS). We measured mean change of IPOS scores and improvement in outcome (any patient with moderate/severe/overwhelming symptoms to not at all/slightly), at first phase change and end of episode of care.

Results: 4575 patients received 5209 episodes of care. At episode level, median age was 80 years (IQR: 69 – 87), 53% females, and 59% had cancer. Most patients presented in 'deteriorating' (46%) and 'unstable' (23%) Phase of Illness at the start of episode. By first phase change, mean 'pain' score reduced from 1.24 to 1.09 (31% of 846 patients with moderate/severe/overwhelming pain improved); mean 'breathlessness' score reduced from 0.88 to 0.79, (31% of 582 patients improved); mean 'anxiety' score reduced from 1.20 to 0.97 (26% of 408 patients improved); and mean 'feeling depressed' score reduced from 0.7 to 0.6 (32% of 241 patients improved). By end of episode, mean 'pain' score reduced from 1.24 to 0.78 (58% of 631 patients improved); mean 'breathlessness' score reduced from 0.88 to 0.60, (54% of 437 patients improved); mean 'anxiety' score reduced from 1.20 to 0.63 (59% of 278 patients improved); and mean 'feeling depressed' score reduced from 0.75 to 0.42 (60% of 156 patients improved).

Conclusions: This analysis demonstrates how community care hospices can systematically use routinely-collected outcomes data to demonstrate the positive impact of the care they provide.

Funding: Yorkshire Cancer Research (L412)

P 5 Plenary

Abstract number: D-06
Abstract type: Best Oral

Is Palliative Care Provision Associated with Prevalence of Death in Hospital at the Population Level? Evidence from 30 European Countries in the Years 2005-2017

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Background: Studies of individual-level data report that palliative care (PC) availability is associated with lower risk of death in hospital.

Aims: We compiled a cross-national longitudinal dataset to identify population-level factors associated with hospital mortality rate in Europe across the years 2005-2017.

Methods: We sought place of death data from the national statistics offices of the 32 EU-EEA countries. Data on PC availability by country were collected from the European Association of Palliative Care (EAPC) Atlases. Our primary predictor of interest was binary: in a given nation in a given year, did the PC provision meet EAPC recommendations, controlling for population size and age? We collected additional predictors from Eurostat, OECD and WHO: national wealth, societal factors, population health, and health system variables. We used linear regression with panel-corrected standard errors to assess association between hospital mortality rate, PC availability and other factors.

Results: Our final dataset included 30 EU-EEA countries, missing Greece (no outcome data) and Liechtenstein (no PC provision). Average hospital mortality rate ranged from 27% to 67% over the study period, with notable differences between Eastern, Southern and North(west)ern nations both cross-sectionally and over time. The regression analysis found PC provision in line with EAPC recommendations was associated with 3% lower hospital mortality rate (95% CI: -5.3% to -0.8%; p=0.01). Low HDI countries were significantly associated with high hospital death, with south countries showing the highest hospital death rate. Government funding of long-term care, and lack of assistance in functional issues were also significantly associated with reduced hospital mortality.

Conclusion: PC access increased in the study period and was associated with lower hospital mortality. Significant associations between outcome and economic, societal, and health system factors were identified in our analysis.

P 6 Plenary

Abstract number: B-04
Abstract type: Best Oral

Analgesic Prescribing Patterns for People Dying with and without Dementia in the UK: General Practice Cohort Study

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Background: People with dementia may not receive appropriate analgesia towards end of life.

Aims: To explore how analgesic prescribing changes over the last year of life for people dying with and without dementia and how palliative care register (PCR) codes impact on this.

Method: Retrospective study of the Health Improvement Network (THIN) database of UK primary care health records (>12 million patients from 711 practices). Participants aged 59-100 at time of death (2008-2017) grouped by: 1) dementia +PCR n=11,093, 2)no dementia +PCR n=54,742, 3) dementia -PCR n=39,140, 4)no dementia -PCR n=177,746. Cohort described by sex, age at death, deprivation, co-morbidity (standard prescribing index) and time to death from when palliative care need was recorded. We extracted prescribing data on simple analgesics, weak opioids and strong opioids. We modeled and graphed the proportion prescribed analgesics per week fitting multi-level mixed effects Poisson regression, adjusting for sex, age at death, deprivation and co-morbidity. We repeated this using independent Poisson regression by type of analgesic.
Results: In the last year of life analgesics were prescribed to

1) 38.0% dementia +PCR,
2) 39.0% no dementia +PCR),
3) 35.2% dementia -PCR,
4) 33.1% no dementia -PCR.

Three months before death strong opioids were received by

1) 47.5% dementia +PCR,
2) 61.2% no dementia +PCR),
3) 32.8% dementia -PCR
4) 39.8% no dementia -PCR.

Graphs of Poisson regression for last year of life by groups showed people with dementia remained on simple analgesics with increased opioid prescribing 1 week prior to death. Group 2 (no dementia +PCR) switched from simple analgesics/weak opioids to strong opioids for the last 25 weeks. For no dementia -PCR this occurred during the last 12 weeks of life. We also present trends by calendar year.
Conclusion: Those dying with dementia are prescribed opioids closer to death than those dying without
Funder: Marie Curie Care Core Grant [MCCC-FCO-16-U]

Free Communication sessions

FC 01 Measuring and Managing Symptoms

Abstract number: B-05
Abstract type: Oral

Cost-effectiveness of Sustained-release Morphine for Refractory Breathlessness in COPD: A Randomized Clinical Trial

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Background: Breathlessness is a common symptom in patients with advanced chronic obstructive pulmonary disease (COPD) and has major impact on quality of life, daily activities and healthcare utilization. Oral morphine is used as palliative treatment, but evidence on cost-effectiveness is lacking.
Aims: To analyze the cost-effectiveness of regular, low-dose morphine in patients with advanced COPD from a healthcare and societal perspective.
Methods: We conducted a randomized double-blind intervention study in patients with advanced COPD and refractory breathlessness. Patients were randomized to 20-30 mg regular, oral sustained-release morphine or placebo for four weeks. Patients completed a prospective cost diary addressing healthcare utilization, productivity, and patient and family costs. We assessed disease-specific quality of life (COPD Assessment Test; CAT) and quality-adjusted life years (QALY's; EQ-5D-5L) in order to calculate incremental cost-effectivity ratio's (ICER) - using healthcare costs and CAT scores - and incremental cost-utility ratio's (ICUR) - using societal costs and QALY's. We performed several sensitivity analyses to assess robustness of the results.
Results: Data of 106 of 124 participants was analyzed, of which 50 were in the morphine group (mean [SD] age 65.4 [8.0] years; 58 [55%] male). Both the ICER and ICUR indicated dominance for morphine treatment. Sensitivity analyses substantiated these results. From a healthcare perspective, the probability that morphine is cost-effective at a willingness to pay €8000 for a minimal clinically important difference of 2 points increase in CAT score is 63%. From a societal perspective, the probability that morphine is cost-effective at a willingness to pay €20,000 per QALY is 78%.
Conclusion: Regular, low-dose, oral sustained-release morphine for 4 weeks is cost-effective regarding the healthcare and the societal perspective. A study of longer follow-up is warranted to estimate long-term costs and effects.

Abstract number: B-06
Abstract type: Oral

Healthcare Resource Utilisation by Patients with Advanced Cancer Living with Pain: An Analysis from the STOP Cancer Pain Trial

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Background: Globally, about 70% of patients with advanced cancer experience pain. Few studies have investigated healthcare use in this population and the relationship between pain intensity and costs.
Aims: To identify pain features, treatment patterns and healthcare costs in people with advanced cancer and pain to inform future health care delivery.
Methods: Adults with advanced cancer and pain (⩾2/10 numeric rating scale (NRS)) were recruited from 6 Australian oncology/palliative care outpatient services to the STOP Cancer Pain trial (Aug15-Jun19). Study data were linked to routinely collected information about out of hospital services and prescriptions for consented participants. Total costs were estimated for the 3 months prior to pain screening. Clinico-demographic variables, health services, treatments, NRS pain and healthcare costs were summarised with descriptive statistics. Relationships with costs were explored using Spearman correlations, Mann-Whitney *U* and Kruskal-Wallis tests, and a gamma log-link generalized linear model.
Results: Overall, 212 consented participants, with an average pain score of 5.3 (SD 2.3), were included. The top 5 most frequently prescribed drug therapeutic categories were opioids (60.1%), peptic ulcer/GORD drugs (51.6%), antiepileptics (26.6%), corticosteroids (25.5%) and other antineoplastics (23.9%). A third of participants received chemotherapeutic procedures (33.3%). The total average healthcare cost was $6,742 (median $4,248) and gender was the only variable associated with healthcare costs (unadjusted men $7,924, women $5,367, U=3546, p=0.04; adjusted men $7,872, women $4,493, W^2 11.49, $p<0.01$).

Conclusion: The findings reveal interesting treatment patterns for outpatients with advanced cancer and pain requiring further exploration such as the high use of peptic ulcer/GORD drugs, and higher healthcare costs for men.

The STOP Cancer Pain trial was funded by the Australian National Breast Cancer Foundation.

Abstract number: B-08
Abstract type: Oral

Longitudinal Symptom Profile of Palliative Care Patients Receiving a Nurse-led End of Life (PEACH) Program to Support Preference to Die at Home

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Background: Provided symptoms can be adequately controlled many people at the end of life prefer to be cared for and, often, die at home. The PEACH model of care is a rapid response nurse-led package of care mobilised for palliative care patients who have an expressed preference to die at home. In tailored models of home-based care aimed to support death at home, it is important that symptom control is also optimal.
Aims: To explore symptom occurrence and level of symptom distress over time in patients receiving a PEACH package by mode of separation.
Methods: Prospective cohort study of consecutive PEACH package recipients (Dec 2013 - Jan 2017). Eligibility for PEACH required deteriorating/terminal phase of illness, poor performance status and preference to die at home. Variables included sociodemographic, clinical characteristics and symptom distress (Symptom Assessment Score (SAS) at each visit). Descriptive statistics and forward selection logistic regression analysis were used to explore influence of symptom distress levels on mode of separation (died at home, admitted to hospital/palliative care unit or alive/no longer requiring PEACH) across 4 symptom distress level categories (0, $>$ 0 - 3, $>$ 3 - 6 and $>$ 6 -10).
Results: 1,754 clients received PEACH package over study period (mean age 70 yrs, 55% male). 75.7% (n=1327) had a home death, 13.5% (n=237) were admitted or Palliative care Unit and 10.8% (n=190) were alive. Mean symptom distress scores improved from baseline to final scores in the three groups ($P<0.0001$). Frequency of no symptom distress (0) category was higher in the home death group. Higher scores for nausea, fatigue, insomnia and bowel problems were independent predictors of who was admitted to hospital.
Conclusion: Tailored home-based palliative care services to meet preference to die at home, achieve this whilst maintaining symptom control. Response to increase in particular symptoms may further optimise these models of care.

Abstract number: L-08
Abstract type: Oral

Identifying the Consequences of Restrictive Visitor Policies on Palliative Care Providers, their Patients and Caregivers

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Background: Restrictive institution visitor policies were implemented to minimize infection risks during the COVID-19 pandemic. Little data exists on the relationship between these policies and the provision of palliative care(PC).
Aim: To describe the experiences and reflections of PC physicians on the effects of restrictive visitor policies.
Methods: Semi-structured interviews were conducted with physicians about their experience providing PC in institutions with restrictive visitor policies. Thematic analysis was used to describe and interpret overarching themes.
Results: Twelve specialized PC and 11 primary PC were interviewed. Interim analysis of 16 coded interviews demonstrates 4 main thematic categories including patient, caregiver, provider, and system effects. Patient-related items included isolation, dying alone, lack of caregiver advocacy and forced care decisions to allow for visitor presence. Caregiver factors included the inability to support or provide care to patients, poor communication with care teams, poor illness understanding, the need to make distanced care decisions, and challenges in identifying visitors. Provider factors included increased time and effort on communication, lack of caregiver input on patient status, increased complaints, the need to be a caregiver surrogate, visitor advocate or gatekeeper. System effects included the increased interest to be provided care in the community and the lack of interest in palliative care units. These factors were often exacerbated by several issues including the lack of clear evidence on their validity, and inconsistent enforcement or interpretation of policies at the unit, which led to patient and caregiver anger and distrust, and provider frustration.
Conclusion: Preliminary analysis highlights substantial negative consequences of restrictive visitor policies at the patient, caregiver, provider and system levels which were exacerbated by their lack of evidence and inconsistent enforcement.

Abstract number: L-13
Abstract type: Oral

Factors Influencing Acceptance or Refusal of Palliative Care among Patients with Moderate to Severe Symptoms: A Qualitative Study

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Background/Aim: Early palliative care improves quality of life for patients with advanced cancer but is not feasible or necessary for all patients. Symptom screening with Targeted Early Palliative care (STEP) is a novel intervention that targets patients with high symptom burden. The effectiveness of STEP vs. usual oncology care was explored in a randomized controlled trial. In the STEP arm, patients reporting moderate to high symptoms received a triggered call by a nurse offering a referral to a palliative care clinic; the patient could accept or decline. We explored patients' reasons for accepting or declining this referral.
Methods: STEP participants who had received a triggered phone call were recruited for this qualitative descriptive sub-study. Semi-structured interviews (n=9) were conducted over the phone and ranged from 30-90 minutes; recruitment to this study remains ongoing. Interviews were transcribed verbatim, and the accuracy of the transcripts was verified. Five investigators performed thematic analysis; themes were discussed until consensus was reached.
Results: The concept of readiness was an overarching theme. Reasons for accepting the referral included: to manage symptoms, to get support to cope with uncertainties surrounding the future, and to start a therapeutic relationship. Reasons for declining the referral included: feeling adequately supported by caregivers, perceiving their symptoms as normal, needing time to process information, and fearing the unknown.

Conclusion: Our study revealed several reasons why symptomatic patients may accept or decline a palliative care referral. This information is important to guide the provision of timely palliative care for those who need it most.
Funding: CIHR

FC 02 Advance Care Planning and Cardio-Pulmonary Resuscitation

Abstract number: D-01
Abstract type: Oral

Do Physicians Discuss Cardio-pulmonary Resuscitation (CPR) Prognosis with Hospitalized Older Patients? An Analysis of Admission Interviews

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Background: International standards stipulate that a patient's wishes regarding Cardio-Pulmonary Resuscitation (CPR) have to be elicited when hospitalized. To date, there is little research based on natural data regarding how physicians explain CPR.
Aims: To investigate whether and how physicians and patients discuss CPR prognosis at hospital admission.
Methods: We audio-recorded hospital admission interviews of 51 patients performed by 17 physicians. We used quantitative content analysis to determine whether CPR prognosis was discussed, and who initiated this discussion. We used thematic analysis to investigate how CPR prognosis was discussed.
Results: CPR in general and CPR prognosis specifically were discussed in 43 (84%) and 22 (43%) of the 51 interviews, respectively. Discussion of CPR prognosis was brought up by physicians in 10 cases and by patients in 12 cases. The main themes associated to discussion of CPR prognosis were chances of survival and risk of impairment. Physicians usually highlighted the unpredictability of CPR outcomes ("We don't know what we'll be able to achieve"), were elusive as to providing factual details ("It's a procedure that involves risks") and scarcely referred to the patient's individual prognosis. While patients don't refer to chances of survival, they summon the element of hope in regard to remaining alive ("when there's life there's hope") which, implicitly, displays their understanding of CPR prognosis. Risk of impairment ("becoming a vegetable") is often cited by patients who prefer to eschew CPR.
Discussion: Although a general discussion about CPR occurred in most interviews, its prognosis was specifically discussed in less than half of them. Yet, explaining CPR is essential for equipping patients to make autonomous decisions about their future care. Our findings highlight the need to improve physicians training to better support patients in making informed decisions.
Funding source: Service of a university hospital

Abstract number: D-13
Abstract type: Oral

Advanced Care Planning in Nursing Home Patients with and without Cognitive Impairment who Are at the End of Life

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Background: Advanced care planning is crucial to develop an adequate end-of-life care in nursing homes. Aims: Describe the advanced care planning of patients of nursing homes at the end of life, as well as the differences in decisions reported by patients with or without cognitive impairment.
Methods: Descriptive cross-sectional study. Palliative patients were identified with the NECPAL tool from 8 nursing homes in southern Spain in January 2020. Nurses completed an ad hoc form in which they were asked to indicate the decisions that were planned or explored with patients or relatives of patients with cognitive impairment. Cases with dementia and without cognitive impairment were compared with Student's t-test.
Results: 124 cases (66.1% of them women) with a mean age 84.69 years (8.12) were analyzed. 46% of the patients showed cognitive impairment. In 81.5% of the cases, patients or families indicated that they preferred to be transferred to the hospital. In 69.4% of cases patients or families preferred intravenous hydration if it was necessary. In a high percentage several decisions were not explored; In 75.8% of the cases, the possibility of palliative sedation was not explored and in 75.8% DNR orders were not discussed with patients or cognitive impaired patient's relatives. Only in 55.6% of all cases a patient's representative was identified. In cognitive impairment patients the percentages of cases where DNR (98.2% vs 86.6%; $p = .017$) and blood transfusion (84.2% vs 65.7%; $p = .019$) was not discussed was higher.
Conclusion / discussion: End-of-life decisions need to be explored and representatives need to be identified in nursing homes.

Abstract number: M-12
Abstract type: Oral

Advance Care Planning in Primary Care for People with Gastrointestinal Cancers: A Feasibility Trial

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Background: Advance care planning (ACP) can benefit more people with advanced cancer.
Aim: A feasibility trial of ACP in primary care for oncology patients with advanced upper gastrointestinal or pancreatic cancer had the primary outcome: care planning discussion with a general practitioner (GP) and a documented ACP. Secondary outcomes: trial feasibility, acceptability and quality of life.
Methods: Mixed method, convergent design at a UK cancer centre. Intervention patients received a letter to their GP, and ACP information from their oncologist, copied to the GP. All participants completed postal questionnaires for quality of life, wellbeing/capability and decision-making (EuroQol EQ5D-5L, ICECAP Supportive Care Measure, CollaboRATE) at baseline, 6, 12, 24, 48 weeks. Purposive sample of patients, carers, and GPs (n=53) interviewed at 8 and 20 weeks. Quantitative analyses by Clinical Trials Unit in parallel with qualitative analyses. Findings integrated and informed by Theory of Planned Behaviour.
Results: Feasibility measures for recruitment, participation and retention achieved. Screening excluded many people unfit for oncology treatment. Of eligible patients, 77% randomised (25 intervention, 21 control). Overall, there were 29 (63%) deaths during the study. Participants contacted GPs but the intervention had no impact on documented ACPs. Quality of life and ICECAP measures (except physical functioning) were high despite demanding cancer treatment and deteriorating health. Interviews explored motivational factors for patients, caregivers and GPs. Attitudes about normality, social norms of fighting cancer/maintaining hope, and perceived behavioural control hindered ACP.

Conclusions: This mixed method study integrated quantitative and qualitative data, and used behavioural theory to explore complex barriers to ACP. It can inform ACP implementation in primary care where specialist interventions to support adjustment and coping are not available.

Funder:
Macmillan

Abstract number: N-01
Abstract type: Oral

When to Initiate Advance Care Planning Conversations in Patients with Advanced Cancer? Results of the ACTION Trial

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Background: Timing of advance care planning (ACP) in patients with advanced cancer is challenging. If the process is initiated too early, patients may not be ready. Yet, delaying ACP may leave insufficient time for patients and families to prepare.

Aims: To evaluate the experience of timing of ACP conversations among patients with advanced cancer, and its potential impact.

Methods: We used data from the ACTION cluster-RCT across six countries (Belgium, Denmark, Italy, Netherlands, Slovenia, and United Kingdom) including patients with advanced lung or colorectal cancer with a life expectancy of approx. one year. The ACTION Respecting Choices ACP intervention included scripted ACP conversations between patients, family members, and certified facilitators. Participants' experience of the timing of ACP was measured at 12 and 20 weeks by: "How did you feel about the timing of your ACP conversations during the study in relation to where you find yourself in your life at the moment?" Answering options were too early, just about right, and too late.

Results: Of 442 intervention patients, 396 (90%) engaged in ACP of whom 301 (68%) answered the question about timing. Of these, 16% considered the timing to be too early, 75% just right, and 8% too late. Experiences of timing were associated with gender (women more often found it too early, p=0.02) and country (more often too early in Denmark and too late in Slovenia, p=0.02). Timing was more often considered too late with worse performance status (p=0.009). When timing was considered right, conversations were perceived as more helpful ($p<0.001$) and less stressful (p=0.01). When timing was considered as too early, advance directives were less often included in medical files.

Conclusion: Adequate timing of the initiation of ACP conversations improved acceptance and efficacy of ACP. Evaluation of timing was not only associated with clinical characteristics such as performance status, but also with personal and cultural factors.

FC 03 Innovation and New Technologies

Abstract number: A-02
Abstract type: Oral

Measurement Equivalence of the Paper-based and Electronic Version of the Integrated Palliative Care Outcome Scale: A Randomised Crossover Trial

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Background: The paper-based Integrated Palliative Care Outcome Scale (IPOS) validly and reliably measures the complex symptoms and concerns of those receiving palliative care.

Aim: To determine the equivalence of the conventional paper version with an electronic (tablet/PC/smartphone-based) version of the IPOS.

Methods: Multicentre randomized crossover trial with a within-subject comparison of the two modes. Washout between the two administrations was 30 min. A convenience sample of inpatient and specialist palliative home care patients aged over 18 years with cancer and non-cancer conditions was recruited. Scores were compared using intraclass correlation coefficients (ICCs), Bland-Altman plots, and via a mixed-effects analysis of variance.

Results: A total of 50 patients were randomized to order paper-electronic ($n = 24$) and electronic-paper($n = 26$) with median age 69 years (range 24 – 95), 56% male, 16% non-cancer. The ICCs showed very high concordance for the total score (ICC 0.99, 95% CI 0.98 – 1.00), with the lowest ICCs being observed for symptoms Appetite loss and Drowsiness (ICC 0.95, 95% CI 0.92 – 0.97). Nine of 17 items had ICCs above 0.98, as did all subscales. No statistically significant mode, order, age, and interaction effects were observed for the IPOS total score and its subscales, except for the Communication subscale (F_{mode}=5.9, $p = .019$). Patients took a mean of 5.82 min to complete the paper and 5.81 min to complete the electronic version, with patients older than 75 years needing more time for both modes. 58% preferred the electronic version. In the group 75+ years, 53% preferred the paper version. Only 3 entries in the free-text main problems differed between the versions.

Conclusion: The very high equivalence in scores and volunteered symptoms/concerns between the paper and the electronic version of the IPOS demonstrates that electronic capturing of outcomes is feasible and reliable in an older palliative population.

Abstract number: A-04
Abstract type: Oral

Developing a Digital Game to Improve Public Perception of Dementia

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Background: There is a pressing need to ensure that generations understand what dementia is and how to support people in the community living with dementia. Whilst this is slowly being addressed more is needed to enable people with dementia to receive the respect and support they need to continue to live active and healthy lives. Digital gaming is becoming a common way to educate and train healthcare professionals and the public about different healthcare topics. Therefore, the aim of this study is to develop an initial version of a digital game that will improve public perception about dementia.

Aims: To develop an initial version of a digital game that will improve public perception about dementia.

Methods: Focus groups were conducted with people living with dementia to share emotionally significant experiences of life in their community. Key themes from these stories were used as prompts in a co-design workshop with university students and people with dementia in developing the priorities and objectives of the game. Further co-design workshops were held to develop the game content and design. An initial version of the game was then tested with local university students who completed a questionnaire before and after using the game to see if their awareness of dementia had changed.

Results: Four focus groups were held with 20 people living with dementia. Three key themes from these meetings consisting of 30 key points were used in the game co-design workshops. The initial version of the game was played by 1000 students, of these nearly 500 completed both questionnaires. Significant improvement in dementia awareness has been found.
Conclusion / discussion: The initial version of the game has proved a success not only with the co-design process used but, it has also given players an improved awareness of dementia. The game now needs to be developed into a final version and tested with a wider range of people in the community.

Abstract number: A-06
Abstract type: Oral

Development and Evaluation of a Web-based Program for Advance Care Planning

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Background: Web-based programs may improve access to advance care planning (ACP), but they are not widely available and only a limited number of programs is evidence-based.
Aims: To develop the first web-based ACP program in the Netherlands, and to evaluate users' experiences and engagement in ACP before vs. after using the program.
Methods (design, data collection, analysis): We developed an interactive web-based ACP program, called "Explore your preferences for treatment and care", to guide users through the ACP process and to support them in shared decision making. The content was based on a scoping review, an interview study and input of patients and healthcare professionals. In a pilot study, six patients with a chronic disease and three doctors completed and evaluated the program. In a subsequent evaluation study among 147 patients with a chronic disease, we assessed their engagement in ACP using the validated ACP Engagement Survey before and two months after program completion (score 1-5); the program's usability (score 0-100); and user satisfaction (score 1-5). Subsequently, the program was launched, embedded in the nationwide frequently used platform Thuisarts.nl ('homedoctor.nl'), which is hosted by general practitioners.
Results: The pilot study showed that the program was understandable and usable. In the evaluation study, overall ACP engagement increased from 2.8 before to 3.0 two months after program completion ($p<0.001$). Contemplation about ACP increased from 2.6 to 2.8 and Readiness for ACP from 2.2 to 2.5 ($p<0.01$). The program was perceived as usable (mean score 70, SD=13), and users were satisfied with its attractiveness (3.8, SD=0.7) and comprehensibility (4.2, SD=0.6). Following its launch in April 2020, the program has been frequently used (>30.000 visits by December 2020).
Conclusion / discussion: The Dutch interactive web-based program "Explore your preferences for treatment and care" is usable and understandable. Our results suggest it can support people in thinking about ACP and in taking the first ACP steps.
Link to the program: https://www.thuisarts.nl/keuzehulp/verken-uw-wensen-voor-zorg-en-behandeling.

Abstract number: A-07
Abstract type: Oral

'Educating RITTA': Evaluation of an Artificial Intelligence Programme in Opioid Prescribing - A Pilot Project and Needs Assessment

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Background/aims: Through a person centred, design thinking process, our cancer hospital palliative care team in conjunction with IBM Watson developed an Artificial Intelligence (AI) enabled virtual assistant, trained in giving basic advice on opioids. This dialogue agent is currently trained to answer a limited number of patient generated queries to demonstrate capability. Our patient/carer group suggested a hospital virtual chatbot, that could answer queries at any time of day or night.
Methods: Patients, carers and healthcare professionals were tasked with creating common queries and answers around opioid prescribing. Questions and answers were programmed into the IBM Watson machine learning appliance 'RITTA' (Realtime Information Technology Towards Activation) with help from IBM IT engineers.
Results: Phase 1 testing results: 10 patients in a palliative care outpatient clinic who had recently been prescribed opioids, were invited to write down questions on the topic of these medications in palliative care. These queries were put to RITTA after the first programming phase. 50% of questions were answered well, with further programming needs identified due to language specifics, human misspellings, dialects, jargon and variations. Programming weaknesses were also identified.
Conclusions: A key theme in the development of AI is the time, care and resources required to develop Machine Learning (ML) layers. Technical work included expanding patient generated queries and machine learning in areas like palliative opioid prescribing, where a lot of repetition occurs and human medication errors or omissions can happen repeatedly and cause harm. Machine learning in palliative care has potential, but will require significant time commitment to enter thousands of question/answer variations, even for small topic areas. We identified a need for local language, slang/dialect programmes, as well as check systems on how up to date clinical guidance remains.

Abstract number: A-09
Abstract type: Oral

Implementation of eHealth Interventions to Support Assessment and Decision Making for Residents with Dementia in Care Homes: A Systematic Review

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Background: As dementia progresses, increasing symptoms cause considerable distress. Integration of care between care homes and healthcare services is vital to meet rising care needs. eHealth can facilitate this, by enabling remote specialist input on care processes such as comprehensive assessment and decision making. How best to implement eHealth in the care home setting is unclear. This review aimed to identify key factors that influence implementation of eHealth for people living with dementia in care homes.
Methods: A systematic search of EMBASE, PsychInfo, MEDLINE and CINHAL was conducted to identify studies published between 2000-2020. Eligible studies focused on eHealth interventions to improve assessment or decision making around care and treatment for residents with dementia in care homes. A narrative synthesis using thematic analysis methods was conducted. The data was deductively mapped onto the six constructs of the adapted Consolidated Framework for Implementation Research (CFIR).
Results: 29 studies were included, focusing on a variety of eHealth interventions including remote video-consultations and clinical decision support tools. Key factors which influenced eHealth implementation most commonly concerned the Inner Setting construct of the CFIR, relating to requirements for implementation in the care home. Three novel sub-constructs were identified to capture data pertaining to Patient Needs:

Clinical Benefit, Resident Experience, Patient Centred-Care; and one around end-user engagement: Other Stakeholders.

Conclusions: Implementing eHealth in care homes for people with dementia involves interaction between the resident, staff and organisation. Applicability of the CFIR for care homes requires an emphasis on the needs of residents and inclusion of engagement of end-users in the implementation process. A novel conceptual model of the key factors has been developed, and translated into practical recommendations to guide implementation in care homes.

FC 04 Symptoms and Sedation

Abstract number: B-07
Abstract type: Oral

Clinical Aspects of Palliative Sedation: A Systematic Review of Prospective Studies

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Background: Palliative sedation is a medical intervention aimed at relieving refractory suffering at the end of life. Its practice varies across countries and settings, and the developed clinical guidelines to guide it are based on expert opinion or retrospective chart reviews. Therefore, evidence for the clinical aspects of palliative sedation is needed.

Aim: To explore clinical aspects of palliative sedation in recent prospective studies.

Methods: A systematic review following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines was conducted and registered at PROSPERO. The search strategy combined the concepts of sedation, palliative care and prospective. PubMed, CINAHL, Cochrane, MEDLINE, and EMBASE databases were searched (January 2014-December 2019).

Results: Ten prospective articles were included. Involved patients were mostly oncologic. Most frequent refractory symptoms were delirium (41%-83%), pain (25%-65%), and dyspnea (16%-59%). Psychological and existential distress were mentioned (16%-59%) mostly in combination with another refractory symptom. Only a few articles specified the tools used to assess symptoms and consider them as refractory. Level of sedation assessment tools used were the Richmond Agitation Sedation Scale, Ramsay Sedation Scale, Glasgow Coma Scale, and Bispectral Index monitoring. The studies show palliative sedation practice as well as the underlying need for proportionality in relation to symptom relief. Midazolam was the main sedative used. Patients' level of comfort was measured in only one study, reporting an increase on it.

Conclusion/ discussion: Assessment of refractory symptoms should include physical evaluation with standardized tools applied and interviews for psychological and existential evaluation by expert clinicians working in teams. Future research needs to evaluate the effectiveness of palliative sedation for refractory symptom relief considering patients comfort.

Abstract number: B-10
Abstract type: Oral

Prophylatic Drugs for Irradiation-induced Neurocognitive Decline: A Systematic Review on Efficacy and Outcomes

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Cognitive dysfunction is a concerning adverse effect on patients' functioning and quality of life, particularly following whole brain radiotherapy (WBRT) for metastatic brain tumours (MBT). To mitigate the risk of neurocognitive decline (NC), a few pharmacological strategies have been explored.

Objective: Review evidence for preventive pharmacological interventions limiting the irradiation- induced NC in adults.

Design: Systematic review of randomised controlled trials (RCTs), controlled clinical trials, cohort studies, and case-control studies of any pharmacological treatment used to prevent irradiation-induced NC in MBT, published in English, using MEDLINE / Web Science (2001-2021) databases. Additional studies were identified scanning references. Search used keywords: "drug" "prevention'' ''radiation therapy" ''cognitive dysfunction'' and "memory impairment". Data extracted were summarized using predefined data fields, including study quality indicators.

Results: Four studies fulfilled criteria (2 phase III RCTs - a placebo controlled and a hippocampal avoidance (HA) WBRT protocol controlled). All studies evaluated memantine (MM) (911 patients), a glutamatergic NMDAR antagonist. Despite low rates of use of MM in practice (2.2%) there is evidence that it promotes neurocognitive preservation among patients managed with WBRT. Although significant loss to follow impacted the power of the placebo-controlled RCT, at 24 weeks, delayed recall was borderline-significant and time to any cognitive failure was lower in the MM arm (HR 0.78, 95% CI 0.62–0.99, $p = 0.01$). HA-WBRT (vs WBRT) plus MM better preserves cognitive function and patient-reported symptoms at 6-months. In addition, MM was well tolerated with no additional toxicities compared with placebo.

Conclusions: MM is a safe, modestly effective, and relatively inexpensive drug that can prevent radiation- induced NC in MBT. Robust prospective studies to establish its benefit in more diverse indications are needed.

Abstract number: B-14
Abstract type: Oral

Understanding Palliative Care Needs of People with Frontotemporal Lobar Degeneration (FTLD); Systematic Review

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Background: People with Young Onset Dementia (YoD) such as frontotemporal dementia (FTD) experience a range of symptoms which affect cognition and physical wellbeing. There is inequality of access to palliative care and little is known about palliative care needs.

Aim: 1) to identify prevalence of symptoms in people with FTD which may contribute to 'total pain' and benefit from a palliative approach 2) to identify how these symptoms may impact on Quality of Life (QoL).

Method: Systematic literature review registered at PROSPERO (February 2020). We searched for 'total pain' symptoms (physical, psychological, social, spiritual) and QoL using MeSH terms, keywords combining these with "AND" and a search for FTD (MEDLINE, EMBASE, PsycINFO, CINAHL, LILACS, PubMed). Abstracts were appraised independently by three researchers. Included articles were in English, peer-reviewed, empirical and published 2000-2020. We used Hawkers Quality Assessment tool. Symptom data were extracted and grouped using the framework of 'total pain' and dementia stage. Where possible we calculated pooled prevalence for individual symptoms.

Results: We identified 3,436 papers and included 45 papers for data extraction (observational=43). Most studies were conducted in America (n=10) and Australia (n=8), and sample size varied (n=3-894). Studies were mainly high (n=26) and moderate (n=17) quality. Psychological (36.25%) and physical (39%) symptoms were most commonly explored with fewer social (24.5%) and spiritual symptoms (0.25%).

Conclusion: No studies measured “total pain” symptoms towards end of life in FTD. Research on FTD has mainly focussed on cognitive and behavioural symptoms with little information on other ‘total pain’ domains. Future research should explore the palliative care needs of people with FTD to provide appropriate and effective care. *Funding: ESRC/NIHR EMBED-Care (Empowering Better End of Life Dementia Care) programme grant (ES/S010327/1) and Division of Psychiatry, UCL.*

Abstract number: F-02
Abstract type: Oral

Continuous Deep Sedation until Death (CDS) in France: What Is at Stake for Patients, Proxies and Physicians in the Context of the 2016 Law?

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Background: The French parliament passed a groundbreaking law in 2016 giving patients the right to a continuous deep sedation until death (CDS) under certain conditions. Testimonies pointing to difficulties rapidly emerged.
Aims: We launched a qualitative study in 2017 to examine specific situations where barriers to CDS were identified either by a patient’s proxy or her physician.
Methods: Semi-structured interviewed were conducted by a physician and a social scientist with proxies and healthprofessionals in charge of the patient. 40 interviews were led to investigate 22 cases. Qualitative inductive content analysis was used to analyze the data.
Results: We identified 5 misunderstandings between proxies and medical teams.

1. Patients and proxies ground their request for CDS in both physical and existential suffering; physicians consider only physical suffering.
2. Temporality is problematic: first, patients asking for CDS matured their decision. Physicians start maturing their decision as the patient voices her request. Second, once CDS is started, patients and proxies expect death to occur rapidly. Physicians know the dying process will likely last several days.
3. For patients and proxies, a medical promise of CDS is key. But the physician who promises access to CDS may be a different one when the patient is terminal and does not feel obligated by this promise.
4. Patients and proxies believe the law on CDS will ensure a good death. Doctors perceive CDS to be problematic: it requires increasing drug dosages whilst ensuring death is not hastened.
5. The law gives the patient a right to access CDS, albeit with conditions; physicians are reluctant to comply to patient demands.

Conclusion: This study shows that the law generates a tension between patient’s rights and medical responsability as it unsettles the patient-physician relationship and questions the role of proxies in end of life situations.

Abstract number: Q-02
Abstract type: Oral

Guidelines to Reduce, Handle and Report Missing Data in Palliative Care Trials Co-produced Using a Multi-stakeholder Nominal Group Technique

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Background: Missing data can introduce bias and reduce the power, precision and generalisability of palliative care study findings. Guidelines on how to address missing data are limited in scope and detail and poorly implemented.
Aim: To develop guidelines on how best to (i) reduce, (ii) handle and (iii) report missing data in palliative care clinical trials.
Methods:
Design - modified nominal group technique.
Data collection - patient and public research partners, palliative care clinicians, trialists, methodologists and statisticians attended a workshop and helped to develop missing data guidelines through five steps: (i) summary of the evidence, (ii) silent generation of ideas, (iii) contributing and developing ideas by structured groups, (iv) voting, (v) writing the guidelines.
Analysis - frequency of votes were counted. Notes were transcribed and coded based on the principles of thematic analysis.
Results: The top five of 28 main recommendations were: (i) train all research staff on missing data, (ii) prepare for missing data at the trial design stage, (iii) address how missing data will be handled in the statistical analysis plan, (iv) collect the reasons for missing data to inform strategies to reduce and handle missing data and (v) report descriptive statistics comparing the baseline characteristics of those with missing and observed data to enable an assessment of the risk of bias. Preparing for and understanding the reasons for missing data were greater priorities for stakeholders than how to deal with missing data once they had occurred.
Conclusion: The first co-produced comprehensive guidelines on how to address missing data recommend that internationally trialists designing and conducting studies in palliative care should prioritise preparing for and understanding the reasons for missing data, so missing data are prevented in the first place. Guideline implementation will require the endorsement of research funders and research journals.

FC 05 Palliative Care and COVID - Session 1

Abstract number: R-02
Abstract type: Oral

Initiating Advance Care Planning Discussions during Covid-19: A Mixed Methods Study of Healthcare Professionals’ Experiences

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Background: Advance care planning (ACP) is a process of discussion to help people make and record choices about their future care and treatment. COVID-19 has increased the need for ACP, as life and death decisions are made with and for vulnerable people who are likely to die from the virus. There is sparse evidence about how ACP is being managed in nursing homes (NHs) and hospices during the pandemic.
Aims: The study aimed to explore the views and experiences of frontline healthcare staff in NHs and hospices in England, to identify challenges, training and support needs in relation to ACP.
Methods: We used a sequential mixed methods design in two phases. In Phase 1, in-depth telephone interviews were conducted with staff from hospices and NHs. Interview data were transcribed, analysed thematically using NVivo, and used to inform an online survey, which was distributed to NHs in all nine regions of England and 147 adult independent hospices in Phase 2. Numerical survey data were analysed using descriptive statistics, and free text data were analysed thematically.

Results: In Phase 1, 10 interviews took place with hospice (n=6) and NH (n=4) staff.

In Phase 2, 98 surveys were completed, the majority (69.4%) by hospice staff.

Findings from both phases of the study showed differences between hospices and NHs in terms of infrastructure (culture, organisational processes, communication and sharing of information across the health and social care system); autonomy and agency of staff; educational preparation; the ACP process (initiating, documenting, sharing ACPs); and access to and use of technology. In all these areas, hospice staff reported better training, resources and support than NH staff, and higher levels of confidence in facilitating ACP discussions.

Conclusion: Despite local initiatives to provide training around ACP at the start of the pandemic, there remains a need to develop national training and documentation to support ACP in all organisations.

Abstract number: R-03
Abstract type: Oral

Barriers and Facilitators to Specialized Palliative Care Integration for Patients with COVID-19

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Background: Specialized palliative care (SPC) teams are well placed to support patients with advanced COVID-19 in Canada, but evidence indicates integration so far has been variable.

Aim: To understand barriers and facilitators of SPC integration in the management of patients with COVID-19.

Methods: Semi-structured interviews were conducted with physicians across Canada about their experiences providing care to patients with COVID-19. Thematic analysis was used to describe and interpret overarching themes.

Results: Twenty-three physicians (12 SPC, 5 intensivists, 6 general internists) were interviewed. Interim analysis of 16 coded interviews demonstrated that facilitators/barriers to providing COVID-19 care fell into 5 main categories: patient-related, provider-related, Disease-specific, SPC service, and leadership factors. Patient-related items included age, comorbidities, goals, speed of decline and clustering of patients. Non-SPC provider-related factors included experience providing palliative care and working with the SPC team, time, and motivation. Uncertainty around COVID-19 progression, management and infection control practices were identified disease-specific barriers. SPC service factors included stigma related to palliative care, the accessibility, availability, and readiness of SPC services to meet the perceived needs of patients with COVID-19. Leadership facilitators included institutional mandated or supported integration, and SPC? presence at COVID-19 planning tables. Ways to improve integration included educational initiatives, relationship building, formal integrated structures and presence at institutional COVID-19 planning tables.

Conclusion: Preliminary analysis highlights the need for high-level support for formal SPC integrated structures, a SPC role in pandemic planning, and the need for ongoing educational and relationship building initiatives to overcome barriers of SPC integration in COVID-19 care.

Abstract number: R-06
Abstract type: Oral

Care for Dying Patients under the Covid-19 Pandemic in Norway: A Survey of Bereaved Relatives

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Background: Even though Norway has had few deaths from Covid-19, infection control measures have affected most areas of life.

Aims: To investigate how care for the dying was experienced during the first wave of the pandemic.

Methods: Online survey of bereaved relatives using questionnaire based on Care of the Dying Evaluation (CODE) with option for free text comments, accessible July-Oct 2020. Open invitation via websites and newspapers. Analysis by SPSS and thematic analysis.

Results: 102 participants completed the questionnaire, median age group 50-59, 83% women, 61% had lost a parent. The deceased were 46% female, 76% $>$70 years, 48% had cancer, 24% dementia, 5% Covid-19; 83% died March-June. Place of death: 16% home, 34% hospital, 41% nursing home, 8% palliative care units. 71% had restrictions on visiting. While 86% of the relatives perceived medical and nursing care for the patients as good, 35% perceived themselves not adequately supported in the patient’s final days. Free text comments included the following themes: reduced access to staff, reduced quality of care, missing or conflicting information, limitations caused by personal protection equipment, restrictions on visiting, lack of contact from staff during bereavement, but also acknowledgement of staff doing their best under extreme circumstances. “Restrictions on visiting” could be divided into: consequences for the patients, conflicts with staff, limited possibilities for online contact, relatives’ solitude, deprived possibilities for caregiving and follow-up, visiting only on the last two days implying lost possibilities for addressing personal matters and saying good-bye.

Conclusion: Patients as well as relatives were deeply affected by the infection control measures and restrictions on visiting. The most striking finding was that visiting in the last two days could not make up for the lack of visits in the weeks before. Also, follow-up of bereaved relatives is important and often neglected.

Abstract number: R-08
Abstract type: Oral

Experiences, Challenges and Potential Solutions of Generalist Palliative Care in Inpatient Setting during the SARS-CoV2 Pandemic

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Background: During the SARS-CoV-2 pandemic all health care systems faced enormous challenges. Due to increased severity of illness, palliative care patients continued to require comprehensive care. In order to provide general palliative care during a pandemic, experiences of staff should be utilized.

Aim: Description and analysis of experiences, challenges and potential solutions of multiprofessional hospital staff in general palliative care with regard to care of severely ill and dying patients (with/without SARS-CoV-2) and their relatives.

Method: After ethical approval qualitative semi-structured online focus groups were conducted. Individual interviews were also used when necessary. The results were recorded, transcribed, and analysed with the qualitative content analysis by Kuckartz.

Results: Five focus groups having four to eight participants and one additional individual interview were conducted. The participants either work in intensive care, isolation wards or with patients being exceedingly burdened (e.g. dementia).

Fifteen main categories with two to eight subcategories were formed. Patients, relatives and staff as well as visitation regulations and farewell were elaborated as most important main categories. Subcategories are for example insecurity, strain and reprocessing or with regards to visitation: restraints, guidelines or exceptions. The biggest challenge addressed by all interviewees were visitations as the restrictions caused a lot of suffering for everyone involved.

Discussion: Current general precautions and general palliative care are insufficiently meeting the needs of severely ill and dying patients. Their needs are still existing throughout the pandemic and should be addressed accordingly. Interprofessional and -disciplinary cooperation is a precondition for individualised care of seriously ill patients and their relatives. Measures preventing infections (e.g. concepts) should be transparently communicated in hospitals.

Funding: BMBF

Abstract number: R-09
Abstract type: Oral

Changes in Patterns of Mortality and Place of Death during the COVID-19 Pandemic: A Retrospective Analysis of Data from the Four Nations of the UK

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Background: The COVID-19 pandemic has led to excess mortality globally. Understanding change in place of death during the pandemic is needed to help guide resource allocation and support for end-of-life care.

Aims: To analyse the patterns of mortality and place of death in UK (England, Wales, Scotland and Northern Ireland) during the COVID-19 pandemic.

Methods: Descriptive analysis of UK mortality data between March 2020 and February 2021. The weekly number of deaths in each nation was described by place of death using the following definitions: (1) Average deaths estimated using five years of historical data (2015-19); (2) Baseline deaths up to and including expected deaths but excluding COVID-19 deaths; (3) Deaths where COVID-19 is mentioned on the death certificate; (3) Additional deaths not attributed to COVID-19.

Results: During the analysis period, there were 743,172 deaths in the UK, of which 135,716 were COVID-19 related and 17,672 were additional non-COVID deaths. There was variation in mortality between the UK nations with Wales having the highest rate of COVID-19 deaths at 229 per 100,000 population and Northern Ireland the lowest at 141 per 100,000 population. Deaths in care homes increased above baseline levels during the first and second waves of the pandemic but fell below baseline between waves, increasing the most in Wales by 29%. Hospital deaths increased overall by as much as 13% in England but fell by 1% in Scotland. Deaths at home remained above average throughout the study period with an overall increase of between 40-41%. In England and Wales, 15-30% fewer people died in hospices compared to baseline.

Discussion: The COVID-19 pandemic has changed where people die in the UK. Notably a sustained increase in deaths at home has been seen, with implications for planning and organisation of palliative care and community services. Examination of place of death in other countries with high COVID-19 mortality is recommended.

FC 06 Compassionate Communities and Civic Responsibilities

Abstract number: E-02
Abstract type: Oral

Implementing a Compassionate Communities Framework to Raise Public Awareness of Palliative Care in Alberta, Canada

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Background: Despite a rapidly aging population, Canadians remain under-informed and unprepared when it comes to palliative and end-of-life care. A recent Ipsos poll showed that 42 per cent of Canadians lack basic understanding of palliative care. This same survey also showed that 91 per cent of Canadians support the development of information materials to improve knowledge of palliative care, with 85 per cent supporting a full-fledged public awareness campaign.

Aim: To employ a Compassionate Communities approach to increase public awareness and understanding of palliative care within the Canadian province of Alberta (population 4.4 million).

Method: The initial phase of this project consisted of stakeholder engagement, namely: stakeholder analysis, group concept mapping, and a survey of the 34 hospice societies in Alberta about the programs they offer and their interest in future collaboration.

Results: Stakeholder analysis identified networks and strategies for engagement. Local hospice societies across Alberta actively play an instrumental role engaging their own local communities. An environmental scan of these registered hospice societies, their size, mission statements, and the range of programming they offer was collated. Group concept mapping can be used to establish priority action areas. The resulting framework will inform the adaptation of evidence-informed educational tools for uptake in local communities, in partnership with relevant stakeholder organizations.

Implications: The implementation of a Compassionate Communities approach, based on a participatory group concept mapping activity and in collaboration with local hospice societies, provides a framework for other organizations interested in practical examples of this model.

Abstract number: G-02
Abstract type: Oral

The Preferred Place of Burial in the Context of Migration: The Example of Turkish Migrants in Germany

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Background: While (preferred) place of care and place of death are regular topics in the field of end-of-life research, the question of (preferred) place of burial has rarely been raised. Especially in the context of migration, however, this is of increasing importance.

Aims: Using the example of first and second generation Turkish migrants in Germany, the question of the place of burial in the context of migration is discussed.

Methods: We conducted 15 narrative interviews with patients with a Turkish migration history experiencing advanced and non-curable cancer as well as their relatives from Nov-2019/Jan-2021 in Germany. We used Grounded Theory methodology combined with elements of narrative analysis.

Results: There were two key findings: 1) Among the respondents, the question about the "where" of the burial was primarily oriented towards "with whom" (or at least in whose vicinity). Here, respondents differed in whether they wanted to be buried with their family of origin (own parents/grandparents), or alternatively with their spouse, highlighting different understandings of the construct of family. 2) It becomes apparent that the question of the place of burial is not only significant for the dying, but also deeply affects the (further) life of the bereaved. A burial place in Turkey, for example, combined with a perceived obligation to visit this grave, binds the surviving relatives living in Germany to their parents' country of origin. However, this is also associated in part with (emotional) stress.

Discussion: Although the question of the place of burial is not only important for the dying, but also for their surviving relatives, this topic is hardly ever discussed between older first-generation migrants and their children. Here, interculturally sensitized personnel in the field of end-of-life care could make an important contribution to initiating a fruitful dialogue between those affected.

Funding: Deutsche Krebshilfe (DKH 70112492)

Abstract number: J-04
Abstract type: Oral

Civic Engagement Concerning Serious Illness, Dying, Loss and Bereavement: A Systematic Integrative Review

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Background: New public health approaches to palliative care (PC) aim to increase capacity in society concerning serious illness, dying, loss or bereavement, by engaging with civic society. Civic engagement has been described in many domains of health and wellbeing, but a description of the characteristics, processes and impact of the initiatives in PC is lacking.

Aims: To systematically describe and compare civic engagement initiatives in PC in terms of their context, level of community engagement, outcomes, and whether and how they are evaluated.

Methods: A systematic, integrative review of initiatives describing civic engagement concerning serious illness, dying, loss or bereavement in their community. Databases searched: PubMed, Scopus, Sociological Abstracts, WOS, Embase, PsycINFO. By contacting the first authors of the included publications, we obtained additional grey literature. The extracted data was narratively synthesised.

Results: 19 peer-reviewed and 12 grey literature publications were included, reporting on 18 unique initiatives. We found heterogeneity in initiatives in terms of context, development and evaluation. Initiatives exist all around the world, providing activities ranging from social to medical support. Community engagement varies from the community being consulted by researchers, to initiatives being entirely developed by the community. Findings suggest that if initiatives intensely engage with the community, they are more likely to sustain themselves. Initiatives show a variety in their aims and outcomes of evaluation.

Conclusion: Although this review shows a large variety of civic engagement initiatives related to PC, they share some fundamental aspects. They all draw on community engagement, provide mainly social support, and show positive benefits. By providing an extensive description of activities and evaluation methods, this review serves as an inspiration for other initiatives.

Funding: FWO-SBO (S002219N).

Abstract number: J-05
Abstract type: Oral

Compassionate Cities: A Systematic Integrative Review of Existing Initiatives Worldwide

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Background: Compassionate Cities (CC) are community based public health interventions which focus on the community's responsibility in palliative care provision. They apply a set of actions based on the Ottawa Charter for Health Promotion which increases people's control over their own health.

Aim: To review and compare CC with respect to their contextual characteristics, development processes and evaluations.

Methods: A systematic integrative review following the PRISMA guidelines for reporting on systematic reviews. Five databases (Pubmed, Web Of Science, PsycInfo, Embase and Scopus) were consulted including publications from 2005 onwards. This was supplemented with grey literature and author-provided documentation. Data underwent open coding in NVIVO before being narratively analysed.

Results: Twenty-one studies from the peer reviewed search, together with nine from grey literature and two from the author-provided documentation were retrieved, describing twenty-two unique CC. There is substantial variability in what is reported, but all focus on multiple action areas of the Ottawa Charter for Health Promotion. All described CC are exclusively developed in high- or middle-income countries. Activating naturally occurring social connections is a recurring strategy of which the effect in CC is still unclear. Support from local policy makers is identified as crucial to ensure sustainability. Nine articles mention some form of evaluation and although their conclusions are often positive, the evaluated domains and outcomes often do not directly address the formulated aims of the CC.

Conclusion: While the concept of compassionate cities is gaining momentum as a new paradigm for the creation of palliative care capacity across society, only a handful of initiatives have been described. The lack of formal evaluations about their proclaimed health benefits indicates a pressing need for rigorous research about ongoing and future initiatives.

Abstract number: L-16
Abstract type: Oral

Key Areas of Clinical Practice that Enable Optimal Palliative Care in Acute Hospitals: A Mixed Methods Study

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Background: Globally, the epidemiology of dying is changing with people dying at an older age from an expected death.

A high proportion of people require hospital care with the need to strengthen the quality of this care well articulated. Evidence about what enables optimal inpatient palliative care is available. Articulating how to enable this within clinical practice is required.

Aim: To identify the domains of care that are most important to inpatients with palliative care needs and their families and inform how these can be achieved within clinical practice.

Methods: Meta-inference of data obtained via:

1. systematic review and metasynthesis to articulate domains of palliative care that inpatients and their families describe as important; and
2. qualitative research with Australian patients (n=21) and carers (n=29) to enhance understanding of these priorities and how they apply to clinical practice. Meta-inference included:

3. verifying data with palliative care consumers and clinical leaders; and
4. populating joint display tables.

Results: Three categories and 14 domains informing optimal inpatient palliative care, reflecting 1233 patient and 3818 family perspectives, were identified:

1. Person-centred care including respectful and compassionate care; effective communication and shared decision making; effective teamwork; enabling family involvement; and maintaining role, meaning and identity;
2. Expert care including excellence in physical care; impeccable assessment and care planning; effective symptom management; technical competence; patient safety; and supported access to senior clinicians; and
3. Optimal environment for care including patient and family focused structural factors; and cleanliness to support infection control. Data integration identified 68 practice points informing care provision.

Conclusions: This study confirmed three categories of care, 14 domains of importance and 68 practice points that enable optimal inpatient palliative care.

FC 07 Models of Care

Abstract number: L-04
Abstract type: Oral

Enhanced Supportive Care Impact for Patients and Healthcare System

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Background: We set up an Enhanced Supportive Care (ESC) service in our cancer centre to deliver proactive supportive and palliative care to patients alongside anticancer treatment from the point of palliative diagnosis. Whilst well received by patients this service was yet to demonstrate quantitative benefits for patients or systems
Aim: To establish quantitative outcomes for patients and systems resulting from the ESC service
Method: From April 2019-March 2020 we undertook a prospective service evaluation comparing quantitative outcomes for patients accessing ESC compared to average data for matched palliative primary tumour groups. Purposive sampling was used to select patients belonging to specific primary tumour groups. Quality of life data was collected using the Integrated Palliative Care Outcome Scale (IPOS) for ESC attenders and change over time was measured using a single-system design. Other quantitative data included 30 day chemotherapy related mortality, unplanned admissions (regionally), lengths of stay and chemotherapy utilization. These were compared between ESC attenders and the matched-tumour group averages.
Results: 275 patients were selected for evaluation. IPOS revealed statistically and clinically significant reduction in severity scores for pain, weakness, appetite, anxiety and mobility after first appointment with ESC. There was no 30 day chemotherapy mortality in the ESC cohort compared to a 5.4-11.8% mortality in the tumour groups evaluated. Average unplanned admissions for ESC attenders was 0.92 admissions/person/year compared to 2.72 national average in England, resulting in cost avoidance of >£1.5 million over 12 months.
Conclusion: The delivery of our ESC service improved patients' quality of life with significant reductions in symptom burden. There were fewer unplanned admissions and no deaths within 30 days of chemotherapy. These outcomes impacted the wider healthcare economy.

Abstract number: L-06
Abstract type: Oral

Thank Goodness You Are Here: A Pre-post Mixed Methods Study to Assess the Impact of 7-day Specialist Palliative Care on Clinical Outcomes and Experiences of Patients, Carers and Staff

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Background: Ensuring that people with advanced, progressive, life limiting illness have the best possible experience of care, including on weekends, is a societal imperative but little is known about the effectiveness, experiences and econometrics of 7-day services.
Aims: To evaluate the effectiveness and effect of 7-day specialist palliative care (SPC) services on clinical outcomes, patient, carer and staff experiences, and patterns of service utilisation.
Methods: Pre-post mixed methods longitudinal study. Routine data collected retrospectively (baseline) and prospectively from all adult patients accessing 7-day SPC in hospital and community settings in 2 UK sites over 12 months. Interviews with patients, family carers and SPC staff with concurrent thematic analysis.
Results: *(quantitative)* Analysis of 5601 patients' data found trends of less time in hospital (~1 day less), but more frequent admissions (~1.5 admissions more). People with cancer less likely to be hospitalised, with shorter hospitalisations (~4 days fewer). Admissions increased by age, but decreased if female. Length of stay increased for both. Preferred place of death went up: dying in hospital down. There was evidence of efficiency improvements.
(qualitative) 95 interviews (patients n=19; carers n=23; SPC staff n=33 summer/19 n=20 spring/20). Themes of **Responsiveness** (of the service);
Reassurance (patient, carers and staff);
Relationships (between patient, carers and staff, within service and outside);
Reciprocity (between patient, carers and staff, within service and outside) and
Retention (of staff: senior nursing roles were important).
Conclusion: Following initiation of 7-day services there were trends towards reduced stay in hospital, more functional patients accessing support in the community and a reduction in costs. Patients' uncertainty and fear was ameliorated. Staff knowledge and confidence increased. 7-Day services should be developed as they provide high quality, responsive PC.

Abstract number: L-07
Abstract type: Oral

Evaluation of an Enhanced 7-day Specialist Palliative Care Service: Findings from a Quantitative Analysis

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Background: Changes to palliative care service models are common, and yet rarely robustly assessed to understand if they have the desired impact. This is a comprehensive evaluation that aimed to assess whether a change in specialist palliative care service models makes a difference to the type and quality of care received, and hence on important care outcomes.
Aims: To evaluate and evidence the effectiveness and effect of enhanced 7-day specialist palliative care assessment and advice services across two sites on service usage by patients.

Methods: This is a pre-post longitudinal study, combining quantitative datasets from 2 hospitals and 2 hospice units in the UK. Adult (18+ years) patients were sampled from the total population of patients with complex or holistic palliative care needs accessing the 7-day services within the two locality sites and data were collected prospectively and retrospectively (for the baseline period). Data were analysed within 4 time periods of 4 months, with the baseline information (Jun-Sept 2018) compared to the period with the 7-day services (Oct 2018 to Sept 2019).
Results: Data were collected on 5601 patients (1507 pre and 4094 post the enhanced service models started) in 2019-20. The average age was 73 years, roughly equal male/female, and mostly White British. Detailed econometric modelling shows that being older and being female may increase the length of stay, whilst those with cancer, or admitted to the local general hospital have shorter lengths of stay. Whilst no results were statistically significant, there are trends in the data that indicate that people were staying in hospital for less time (around 1 day less), but being admitted to hospital more often (around 1.5 admissions more on average) after the enhanced 7-day service commenced.
Conclusions: Evidence from this study can be used to guide how palliative care services are developed, provided and tailored to maximize the likely benefit that people derive.

Abstract number: L-12
Abstract type: Oral

Specialist Palliative Care Teams and Characteristics Related to Referral Rate: A National Cross-sectional Survey among Hospitals in the Netherlands

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Background: Specialist palliative care teams (SPCTs) in hospitals have positive effects on quality of life and satisfaction with care for patients with advanced disease. However, referrals to SPCTs vary and are often limited.
Aims: In order to identify areas for improvement of SPCTs' service penetration, we examined hospital and SPCT characteristics and assessed their relation with referral rates of these SPCTs.
Methods: We conducted a national cross-sectional survey among Dutch hospitals from March through May 2018. An invitation to complete an online questionnaire was sent to palliative care program leaders in all 78 hospitals. For referral rate (RR) we calculated the number of annual inpatient referrals to the SPCT as a percentage of the number of total annual hospital admissions. RR was dichotomized into high ($\geqslant$ 1%) and low ($<$ 1%). Characteristics of SPCTs with high and low RR were compared using univariate analyses. P-values < 0.05 were considered significant.
Results: In total, 63 hospitals (81%) responded. In 62 of these hospitals palliative care programs consisted of inpatient consultation services (94%), outpatient clinics (45%), dedicated acute care beds (21%) and community-based palliative care (27%). The mean referral rate to SPCTs was 0.85%, with a mean of 0.4% in the low RR group (n=45) and 2.0% in the high RR group (n=17). Comparing these groups showed significant differences with regard to the presence of outpatient clinics and timing of referrals as well as SPCTs' years of existence, staffing, level of education, participation in other departments' team meetings, provision of education and conducting research.
Conclusion: In the Netherlands, specialist palliative care teams in hospitals have varying levels of development, with more mature teams showing higher referral rates. Appropriate staffing, dedicated outpatient clinics, education and research appear means to improve service penetration and timing of referral for patients with advanced diseases.

Abstract number: M-08
Abstract type: Oral

The Role of Emergency Medical Services in the Palliative Care – Scoping Review

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Background: Emergency medical services (EMS) are frequently responding to calls involving patients in advanced stages of incurable diseases. Despite the competencies and potential of EMS in supporting patients and their families facing symptoms of advanced progressive illnesses, the role of EMS in providing palliative care remains unclear.
Aims: This review was conducted in order to systematically map the research published in the area of EMS providing care to patients with palliative care needs. The following research question was formulated: What is the role of EMS, EMS dispatch centres, paramedics and emergency medical physicians in the provision of palliative care to terminally ill patients?
Methods: Following PRISMA-ScR guidelines, online databases CINAHL Complete, MEDLINE Complete (EBSCO), PubMed and MEDLINE (Ovid) were searched from the initial year of database to September 2019. The search was conducted with keywords: "palliative care" OR "palliative" OR „end of life care" OR "terminal care" OR "decision making" AND „Emergency Medical Services" OR „pre-hospital care" (OR "prehospital") OR "paramedics" from the MeSH keywords: Palliative care/organization & administration, Triage/organization & administration and Terminal care. No language restrictions were applied.
Results: 31 articles were included in the qualitative synthesis and 3 main roles and one contextual factor were identified: (1) Providing complex care; (2) Adjusting patient's trajectory; (3) Being able to make decisions in a time and information limited environment; (4) Health care professionals are insufficiently supported in palliative care skills and competences.
Conclusion: The lack of research on the incidence of EMS calls to the end-of-life situations is evident. There are limited data on the incidence of EMS calls to the patients at the end-of-life and no data focusing on the EMS dispatch centres.
Funding: This study was supported by a grant from the foundation "Nadace moudré pomoci".

FC 08 Psychological Symptoms and Communication

Abstract number: H-05
Abstract type: Oral

Let It Out (LIO): A Mixed-methods Study to Optimise the Design of an Online, Emotional Disclosure Intervention for Adults with Terminal Illness Receiving Hospice Care

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Background: The COVID-19 pandemic has accelerated adoption of remote ways of providing hospice care, including psychological support.

Emotional disclosure (ED) interventions hold potential as a way of providing such support online. But evidence supporting use of ED interventions for people living with terminal illness is limited. We are testing an online psychological intervention, Let It Out (LIO), consisting of three self-guided expression sessions over two weeks.

Aims: The primary aim is to inform the development of LIO. Secondary aims include assessing LIO's acceptability, feasibility of study methods and potential impact on wellbeing.

Methods: A mixed-methods, longitudinal study. Adults receiving palliative care were recruited from six UK hospices from September 2020 to January 2021. Participants received the LIO intervention, and completed physical and psychological health-related questionnaires at baseline and immediately, one week, four weeks and eight weeks after the final expression session, with a feedback form after the final session. Two also took part in a semi-structured interview. Focus groups and interviews have also been held with 12 hospice staff and volunteers. Data have been triangulated through process evaluation.

Results: Of 13 patients recruited, 8 have completed all three expression sessions. Most people who finish LIO find it helpful (7/8). One person who withdrew found the online platform too complicated to use. Staff felt LIO could be helpful for computer-literate patients, but reported difficulties with recruitment.

Conclusion: Preliminary evidence suggests LIO holds potential to support wellbeing for some people living with terminal illness. Adaptions are required to make the online platform more user-friendly. This study demonstrates the value of robust consultation with patients and staff in the development of acceptable online interventions for use in palliative care.

Main funding: ESRC and Marie Curie PhD studentship (ES/P000592/1).

Abstract number: H-09
Abstract type: Oral

The Correlation between Suffering and Spiritual Distress in Elderly Cancer Patients: A Cross-sectional Study

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Background: Cancer has an undesirable effect on the patient's health. Spiritual distress and suffering may be experienced in cancer patients throughout the disease journey. Understanding the relation between these concepts is important in order to deliver specific and effective intervention aiming comfort and relief particularly to the elderly.

Aim: To determine the correlation between suffering and spiritual distress in elderly cancer patients.

Methods: Quantitative, observational, correlational and cross-sectional study. A total of 130 elderly cancer patients, aged equal or above 65 years old, were randomly recruited in a Portuguese outpatient setting. Participants filled a questionnaire which included a section with sociodemographic characteristics, clinical condition, Spiritual Distress Scale (SDS) and a question on having experienced suffering. Data collection was executed in four months in early 2019. Statistical analysis was completed using SPSS 24. The project was approved by the Ethics Committee.

Results: 51.5% of the participants were females and 69.20% were married. The average age of participants was 71.75 years (sd=±4.77), ranging between 65 and 83 years. The sample consisted mostly of participants with a religious affiliation (96.90%). The most prevalent diagnosis was breast and colon cancer (21.50%), and concerning the cancer stage, 45.40% have stage III and 36.20% have stage IV.

The mean score of SDS was 54.76 (sd=± 12.38) and 55.40 % of elderly cancer patients experienced suffering. In this study a correlation between suffering and spiritual distress was found (Spearman $= 0.49$; $p = 0.01$).

Conclusion: A moderate correlation between suffering and spiritual distress has been found, which is statistically significant. Suffering and spiritual distress are experienced by elderly cancer patients and the results highlight the need of awareness by healthcare professionals to help patients to overcome this challenging condition.

Abstract number: M-10
Abstract type: Oral

Perceived Quality of Care and Emotional Functioning of Patients with Advanced Cancer and their Relatives: Results of a Multicenter Observational Cohort Study (eQuiPe)

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Background: Previous studies on perceived quality of care (QoC) and emotional functioning (EF) have failed to address the reciprocal relation between patients and their relatives.

Aims: Our study examined the perceived QoC and EF of patients with advanced cancer and their relatives, including their reciprocal relation by using a dyadic approach.

Methods: We analysed data from the eQuiPe study, a prospective longitudinal observational study in patients with advanced cancer and their relatives. Logistic regression analyses were performed on baseline data of 1,103 patients and 831 relatives to assess the association between perceived QoC and EF of patients and relatives separately and across dyads.

Results: Patients experienced lower levels of functioning, including EF, and more symptoms compared to the normative population($p<.001$). Relatives reported even clinically relevantly lower EF compared to patients (69 vs 78,$p<.001$) and were less satisfied with care (59 vs 74;$p<.001$). Being more satisfied with care in general($p<.05$) and clarity about who their central health-care professional is($p<.05$) were positively associated with high EF in patients. In relatives, perceived continuity of care ($p<.01$) and continuity of information for the patient ($p<.05$) were positively associated with high EF while discussing what is important in the care for the patient with health-care professionals was negatively associated($p<.05$). Dyadic analyses showed that EF of patients ($p<.001$) and relatives ($p<.05$) was positively associated with EF of the other person and perceived continuity of care by relatives was positively associated with high EF in patients($p<.01$).

Conclusion: Perceived integral organisation and satisfaction with care in patients and relatives are related to their EF. The additional reciprocal relation between patients' and their relatives' EF and the perceived continuity of care suggests the opportunity for acknowledgement of a family-centered approach to advanced cancer.

Abstract number: Q-01
Abstract type: Oral

Using a Behavioral Theory to Gain Insight into Critical Determinants of Health Promoting Behavior around Serious Illness *a Case Example Applied to Starting a Conversation about Palliative Care*

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Background: Although timely communication is important for timely initiation of palliative care (PC), it is often postponed or avoided. Behavioral theories can be used to better understand and change communication about PC. However, little is known about how such theories can be used to understand health promotion behavior in people confronted with serious illness.
Aim: To describe how behavioral theories can be used to gain insight into critical determinants of health promoting behavior in seriously ill people, using a case example of 'starting a conversation about PC'.
Methods:
Step 1: We chose a theoretical framework.
Step 2: We applied and adapted the selected theory by performing interviews with 25 people with cancer and by using a deductive and inductive approach.
Step 3: We operationalized the determinants of the newly developed behavioral model based on existing surveys assessing determinants of health behavior and results of step 2. An expert group (n= 19) checked content validity. We cognitively tested the survey in interviews with 8 people with cancer.
Step 4: We identified the most important determinants by performing a survey study in 88 people with cancer and conducting logistic regression analyses.
Results:
Step 1: We selected the theory of planned behavior.
Step 2: This theory was found to be applicable to the target behavior, but needed to be extended with the determinants awareness, knowledge and social influence.
Step 3: The final survey included 125 items.
Step 4: The most important determinants were holding a positive attitude towards the behavior (OR 4.26; 95%CI 2.23-8.13) which was positively associated and perceiving barriers (OR 0.31; 95%CI 0.15-0.63) which was negatively associated with the specific target behavior.
Conclusion: This method description provides guidance for researchers and practitioners interested in better understanding or changing the determinants of behaviors in people confronted with serious illness.

FC 09 Older & Frail People

Abstract number: C-03
Abstract type: Oral

Predictors of Pre-death and Post Death Grief in Family Carers of People with Dementia. A Systematic Review

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Background: Caring for somebody living with dementia can have significant emotional implications, including pre-death grief. Whilst a review in 2013 reported prevalence and predictors of pre-death and post death grief, it remains unclear who will experience higher grief. This review aimed to explore factors associated with pre-death and post death or prolonged grief.
Methods: PsycINFO, MEDLINE, CINAHL and ASSIA were searched to April 2020. We included all study types published in English reporting factors associated with grief in informal carers. The evidence was narratively analysed.
Results: Fifty five studies were included. Grief was influenced by carer demographic and psychosocial characteristics, care related features and bereavement factors. Being a spouse, less education, caring for somebody at a more severe stage of dementia and higher levels of burden and depression were associated with greater pre-death grief. Higher predeath grief and depression, less education, and not being prepared for the death were predictive of greater post death grief. Elements of social support were found to have a positive impact on pre-death and post death grief. Perceived social support and social relations were negatively associated with pre-death grief, whilst fewer negative interactions and greater social integration were predictive of lower post death grief.
Conclusion: Demographic, psychosocial, care and bereavement related factors influence pre-death and post death grief. Social support is multifaceted, and understanding what elements support carers with grief, in addition to awareness of characteristics that increase the likelihood of higher levels of grief, can help identify who needs support and the type of support which is helpful. Supporting carers before the death of the person may lead to better bereavement outcomes.
This study is funded in part by Marie Curie and part self funded, and carried out within the Empowering Better End of Life Dementia Care programme.

Abstract number: D-02
Abstract type: Oral

Older People with Severe Frailty Talking about their Palliative Care Needs: An Interview and Survey Study during the Covid-19 Pandemic

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Background: Older people with severe frailty (OPWF) are an unrepresented group in receiving palliative care (PC).
Aim: A modified e-Delphi study nested in a wider mixed method study aimed to understand the most important PC needs for community-residing OPWF.
Methods: The views of OPWF were collected by video-recorded interviews (N=10) and open questions in a facilitated survey (N=10), undertaken October-November 2020. OPWF's ages ranged from 70-99, 11 men, 9 women, living in owned, rented or sheltered accommodation, with Clinical Frailty Scores of 6 (N=8), 7 (N=9) and 8 (N=3). 9 of these participants have now died. Data was analysed using the 5 domains of PC need: physical, psychological, spiritual, practical and social.
Results: Meeting care needs was challenging across all domains. Acute physical needs were responded to, yet important longer-term needs, e.g. mental well-being, rehabilitation, and managing long-term conditions were harder to address. The pandemic caused or worsened distress and anger about being housebound, loss of social contact, increased loneliness and feeling ignored. Access to health and social care was a struggle for OPWF, where previously received services were withdrawn and lack of resources and exposure to telehealth put a high reliance on families to facilitate virtual consultations. OPWF relied on unpaid carers to coordinate and deliver care, which intensified when health deteriorated. Carers vividly detailed the strain and unsustainability of this provision.
Conclusions: Post-Covid learning must take account of the impact on this less-often heard PC population. Prolonged loneliness and reduced activity will have significant consequences for physical and mental health and wellbeing. Unpaid carers are vital to the provision of personalised care to OPWF, they need to be listened to and resourced in their caring work, and to have their own needs assessed and addressed. Funder: HEE/NIHR UK.

Abstract number: D-03
Abstract type: Oral

Symptom Control and Palliative Care Outcomes in Patients at the End of Life in Nursing Homes

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Background: It is expected that a high percentage of people in Spain will die in nursing homes, but the quality of care at the end of life in these centers has not been deeply analyzed.
Aims: To determine symptom control and palliative care outcomes of patients at the end of life in Spanish nursing homes. Methods (design, data collection, analysis): Descriptive cross-sectional study. Palliative patients were identified with the NECPAL tool from 8 nursing homes in southern Spain in January 2020. Nurses completed the Edmonton Symptom Assessment Scale (ESAS) and the Palliative Outcome Scale (POS). T Student test was used to check whether there were differences in both scales scores regarding gender and main diagnosis. Pearson correlation test was used to evaluate correlation with dependency (Barthel) and cognitive status (Pfeiffer index).
Results: 149 cases were analyzed, of which 67.9% were women with a mean age of 84.46 years (SD = 9.12). The mean ESAS score was 2.08 (SD = 1.51). Depression (M = 2.68; SD = 2.47) and fatigue (M = 2.55; SD = 2) were the most intense symptoms described. Regarding POS, the mean score of 13.10 (SD = 5.52). The worst scored item was relatives and friend's anxiety (M = 1.79; SD = 1.23) and patient's anxiety (M = 1.55; SD = 1.04). There are no significant differences according to gender, but ESAS total score was higher in patients with dementia ($p<,01$). The POS score correlates significantly and negatively with Barthel index ($r=-,261$; $p<,01$).
Conclusion / discussion: More attention needs to be paid to the symptoms suffered by patients with palliative needs in nursing homes, especially patients with dementia.

Abstract number: D-11
Abstract type: Oral

Perspectives of Older People Living with Mild Dementia about Eating and Drinking Problems at the Later Stages of Dementia: A Qualitative Study

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Background: Eating and drinking problems can arise at any point in dementia progression, especially at the later stages and the end-of-life. However, we know little about the perspectives of people living with dementia on how they might wish for such problems to be managed.
Aims: This study aimed to understand the experiences and needs of older people with mild dementia about possible future eating and drinking problems.
Methods: We conducted semi-structured interviews with 19 people with mild dementia in September 2019-March 2020 in England. Interviews were transcribed verbatim and analysed thematically.
Results: We identified five themes: 1) awareness of eating and drinking problems; 2) food and drink being part of an individual's identity and agency; 3) delegating later decisions about eating and drinking to family carers; 4) acceptability of eating and drinking options; and 5) eating and drinking towards the end of life. Many people with mild dementia could not relate eating and drinking problems with dementia progression and wanted to postpone discussions until the problems occur. People living with dementia would trust family and professionals to make any decisions. Fears of being a burden to family and of being treated like a child may make them feel reluctant to discuss future problems. People with mild dementia thought they would prefer to maintain a good quality of life, rather than be kept alive at later stages by artificial nutrition and hydration.
Conclusion: Eating and drinking problems may seem currently irrelevant to people with mild dementia. Although they wished to protect their autonomy for as long as possible, they would leave the discussions and decisions to family carers and professionals until the problems occur. Timely, sensitive and repeated opportunities for discussion may encourage the person living with dementia to develop an advance care plan including possible eating and drinking problems, especially for the later stages and the end-of-life.

Abstract number: M-13
Abstract type: Oral

Experiences of a Novel Integrated Care Service for Older Adults at Risk of Severe Frailty: An Analysis of Survey and Interview Data

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Background: Integrated care models involve proactive, multidisciplinary care to support independent community living by reducing hospital admissions in older people ($\geqslant 65$) at risk of severe frailty, in the UK. Evidence exploring patients' experiences of integrated care is limited.
Aim: To explore the experiences of older people at risk of frailty attending a novel integrated care service.
Method: Service experiences were drawn from open-ended survey questions and interview data. Older people ($\geqslant 65$) recruited as part of a service evaluation were asked to complete a short survey. Survey questions collected 2-4 weeks post-assessment, asked about their experiences and recommendations for service improvement. Experiences were also extracted from interviews conducted with a subgroup of patients who reported breathlessness, chronic pain, or unintended weight loss. Survey responses and interviews (audio-recorded and transcribed) were analysed thematically using NVivo software (version 12).
Results: 164/250 (66%) patients responded to the survey. 52/250 were interviewed, of whom 42 (77.4%) reported on their experience of the service. Five major themes were identified from both survey questions and interview data: 1) holistic and person-centred approach, 2) quality of communication, 3) time allocated, 4) positive health outcomes, and 5) advance care planning (ACP). Patients valued the holistic and person-centred approach, the high-quality communication, and the generous time provided for assessments of their health and social care needs. Although ACP was widely accepted, some reported challenges around preparation for ACP discussion. Follow-up and subsequent care after the service were sometimes limited.

Conclusions: Integrated care in this model was viewed as highly beneficial due to its multi-disciplinary, person-centred approach, shared decision-making, and generous consultation time. More preparation for ACP and issues around follow-up care need to be addressed.

FC 10 Education and Workforce

Abstract number: C-08
Abstract type: Oral

Adaptation and Continuous Learning to Start and Persevere in Palliative Care. Revisiting Professional Coping Strategies through an Integrative Review

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Background: Recently, the effects of coping in palliative care (PC) professionals have been studied, but little is known about coping itself. It is necessary to update the evidence on coping strategies, considering the possible professional evolution/development of PC providers.
Aims: To synthesize evidence about professional coping strategies and their role over time in PC.
Methods: An integrative review considering Whittemore and Knafl (2005) was conducted. PubMed, CINAHL, Medline, PsycInfo and B.On were searched, using “coping” and “PC” as keywords. Articles were screened by title and abstract. NVivo software was employed to manage the data. Constant comparative analysis was conducted by two researchers.
Results: Thirty studies were selected. Four strategies were found with a recurrent reference to time: a) proactive coping, entailing activities to achieve self-confidence, control of emotions/situation; b) self-care-based coping, including activities to self-protect and self-knowledge; c) self-transformation coping, entailing activities towards acceptance of limits; and d) deep professional coping, considering deeper meaning of professional work. Dynamic and influential factors were training, team interaction, professional motivation and family. These could be both protectors and, less often, risk factors. Emotional burden and the systemic stressors were always risk factors. The explanatory model shows a dynamic process in which daily and rather introspective strategies are combined. Over time, there is personal and professional transformation related to progressive and greater response, and where demanding situations play a role.
Discussion: The proposed model evidences a learning process to persevere in PC. It changes over time under factors and strategies, and evolves into a personal and professional transformation. Coping in those professionals that have left PC remains unexplored.

Abstract number: E-03
Abstract type: Oral

Objective Structured Clinical Examination (OSCE) in Assessment of Palliative Care Competence of Advanced Nurse Practioner Students

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Background: Palliative care aims to improve the quality of life of patients with life-threatening illness and their nearest ones. In Finland, a new master’s degree education on advanced practice in palliative care was launched in 2019. Comprehensive health assessment is a core clinical competency required from advanced practice nurses. In health sciences, OSCE has been widely used in assessment of clinical competence.
Aim: The aim was to introduce OSCE as an assessment tool and to describe the results of the master degree students’ (n=42) assessments.
Methods: A cross-sectional design was used. Students completed either a case on palliative care patient having symptoms of oral mucositis or respiratory infection. C-CEI© instrument developed by Kirkpatrick was used in the OSCE assessment.
Results: Prior the OSCE, students received short description of the patient coming to an appoint. The appointment with an actor patient was 15 minutes long and included an assessment of the patient’s status and identification of the needs for care. Students received immediate feedback after the OSCE. In the first attempt, 40 out of 42 students passed the OSCE. In average, the students passed with 80% of the total score.
Conclusions: OSCE as an assessment tool suits well for evaluation of clinical competence of students in advanced practice program. Students showed an adequate level of competence in health assessment. The assessment instrument used was originally developed for simulation OSCEs of undergraduate nursing students. The evaluators found the assessment form difficult to adapt to this type of OSCE and therefore it needs further development. The use of the tool in practice requires also more training of the evaluators. OSCEs are used to evaluate clinical competence. However, it is also a tool for learning.

Abstract number: E-04
Abstract type: Oral

Building Capacity for Early Palliative Care within Primary Care Teams: Implication and Evaluation of the CAPACITI Program

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Objectives: Primary care plays a critical role in providing early palliative care (PC), however many primary care providers say they lack the practice supports to operationalize the approach. CAPACITI is a 1-year intervention to help primary care teams implement an early PC approach. We provide an overview of CAPACITI and findings from our evaluation of the first wave of teams that completed this program.
Methods: CAPACITI was based on prior interventions, e.g. Gold Standards Framework, adapted for the Canadian context. It features 10 modules including building a strong team, identifying and assessing patients, communicating and engaging caregivers and specialists. The program offers monthly webinars, accompanied by assigned activities and active facilitation. Our primary outcome was a self-completed 20-item survey of core competencies to providing an early PC approach, measured on a 7-point scale (e.g. level of confidence in identifying all patients requiring PC). Pre and post survey data were analyzed using

paired t-tests. Other data collection included reflections on assigned activities (e.g. create a PC roster) and qualitative measures (e.g. reflect on changes to behavior).
Results: 25 primary care teams completed CAPACITI, representing 105 providers and administrators. All teams participated in qualitative focus groups and 70% of providers completed both pre- and post-intervention surveys. For the primary outcome, Paired comparisons showed a moderate improvement in confidence across the core competencies covered (0.5 to 1.1 mean improvement across items, all $p>0.05$). Specifically, "confidence in identifying all patients requiring PC" improved an average of 1.0 point (SD 1.5). Participants in qualitative interviews stated the program content was highly relevant.
Conclusions: CAPACITI marginally improved confidence in PC identification and in other competencies. The program demonstrated potential for helping primary care teams operationalize an early PC approach.

Abstract number: G-05
Abstract type: Oral

Navigating Tensions between Ideal and Realistic Palliative Care in Socially Deprived Areas: A Multiple Case Study Analysis of Healthcare Professionals' Experiences

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Background: Social deprivation is often associated with poorer health outcomes and difficulties accessing care, including during the palliative and end-of-life phase of an illness. Few studies have explored the experiences of palliative and end-of-life care professionals supporting patients living in socially deprived areas. Understanding their experiences may help facilitate more equitable palliative and end-of-life care.
Aim: To explore the experiences of healthcare professionals providing palliative and end-of-life care to people living in socially deprived areas.
Methods: Semi-structured qualitative interviews were conducted with 42 specialist and generalist palliative care professionals in three regions of North West England as part of a mixed methods multiple case study of hospice referrals and social deprivation. This abstract reports a subset of findings relating to participants' experiences of providing palliative and end-of-life care in socially deprived areas. These findings were generated from an inductive analysis of qualitative data using thematic analysis and cross-case analysis methods.
Results: Participants reflected on their remit and responsibilities when supporting patients in socially deprived areas. There was a tension between professional idealism and the realities of providing palliative and end-of-life care to people experiencing socioeconomic disadvantage. Participants sought to resolve this tension by harnessing a patient choice narrative to justify some patients' end-of-life experiences in socially deprived areas.
Discussion: While there are benefits to facilitating patient choice at the end of life, it risks assuming patients across the socioeconomic spectrum have equal agency over their lives. Palliative and end-of-life care professionals may benefit from discussing different views on appropriate care in the context of social deprivation, and considering the structural factors underpinning patients' circumstances at the end of life.

Abstract number: R-01
Abstract type: Oral

Reflections and Experiences of Physicians Working during the COVID-19 Pandemic: A Qualitative Study

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Background: The need to recognize and attend to physician health and wellness has recently been emphasized, due to high levels of documented distress and burnout. The global pandemic has imposed even greater stressors and novel work demands on clinicians.
Aim: To understand the experiences of physicians providing care during a global pandemic.
Methods: Semi-structured interviews were conducted with physicians across Canada about their experiences providing care to patients during the COVID-19 pandemic. Thematic analysis methodology was used to describe overarching themes.
Results: Twenty-three physicians (12 specialized palliative care, 5 intensivists, 6 general internists) were interviewed. Interim analysis of 16 coded interviews revealed 8 main categories: confusion and uncertainty; exhaustion and burnout; trauma; ethical considerations; isolation; professional re-evaluation; altruism; and cohesion. Confusion and uncertainty related mainly to the novel virus, leadership, and institutional preparedness. Exhaustion and burnout encompassed workload, personal protective equipment, family life, and complexity. The trauma theme included visitor policies, family surrogates, and patient management. Ethical considerations included job demands vs personal and family safety. Isolation was largely related to infection control measures. Professional re-evaluation items included job satisfaction due to changed patient encounters or novel structuring. Altruism items included unique personal contribution to pandemic response and societal needs. Cohesion items included supporting each other and team building.
Conclusion: Preliminary analysis revealed trauma and distress, but also altruism and cohesion. These findings may inform interventions for physician health and wellness, as well as indicating ways to integrate meaning and purpose into negative experiences to promote resilience.

FC 11 Dementia and Care Homes

Abstract number: D-09
Abstract type: Oral

Development of an Advance Care Planning by Proxy Intervention for Residential Aged Care Residents without Decision Making Capacity

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Background: Residential aged care facility (RACF) residents are admitted to RACFs later in life, with increasingly complex care needs. Many already have limited medical decision-making capacity at admission. Advance Care Planning (ACP) shows promising signs of promoting care in accordance with patient wishes, through eliciting treatment wishes and preferences but no ACP by proxy interventions, specifically designed for use with health care proxies of RACF residents without decision-making capacity, exist.
Aims: Explore the needs of health care proxies, RACF health professionals and physicians for ACP by proxy on behalf of RACF residents without decision-making capacity and develop a model of ACP by proxy for this context.
Methods: Three focus groups with 13 RACF physicians, three focus groups with 23 RACF health professionals and 16 semi-structured interviews with 19 health care proxies were conducted. Discussions were transcribed and analyzed thematically using Braun and Clarke's (2006) framework. These results, combined with a review of the existing literature, were used to develop an ACP by proxy model.
Results: Health care proxies wished to be included in planning and decision making systematically, with consistent communication about RACF residents' health and treatments. Health professionals expressed need for tools to identify health care proxies, discussion guides for ACP by proxy discussions, communication training, and clear documentation. Physicians and RACF professionals highlighted the importance of physician presence for discussions of emergency orders, yet time restrictions limit the feasibility. Physicians also highlighted the need for

documentation that is standardised, clearly stipulates treatment limits, quickly understandable in case of emergency.

Discussion: These data were used to develop a model of ACP by proxy for the RACF context: development and implementation will be discussed. Acceptability and feasibility are currently being tested.

Abstract number: D-14
Abstract type: Oral

What Influences Quality of Death and Dying in Dutch Nursing Homes?

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Background/aims: The quality of palliative care for people with dementia is often suboptimal. It is important to understand what is needed from a perspective of relatives to optimize the provision of palliative dementia care. This study explored how the bereaved of people with dementia experienced the overall quality of dying of their loved one.

Methods: A convenience sample of Dutch nursing homes (N=12) routinely collected data from bereaved family caregivers of residents with dementia, from 2018-2020. Families' perceived quality of end-of-life care and quality of dying was measured using the End-of-Life in Dementia Comfort Assessment at Dying (EOLD-CAD), Satisfaction With Care (EOLD-SWC), and Symptom Management (EOLD-SM). Additional open questions concerned families' perception of care provided during the last 3 months of their relative life. Answers to the open questions were thematically analysed. The relationship between demographic characteristics and the EOLD scales were analyzed using multiple regression.

Results: The analyses included 277 relatives (average age 62, 63% female, 70% Son/Daughter). Scores on the EOLD-CAD, SWC and SM were, respectively, 30.47 (range 15 -42), 40.7 (range 12-6036.87 (range 15-54). For comfort, we found negative associations with falls at the end of life, infections and lacking advance care plans (ACP). For symptom management (EOLD-SM), we found negative associations with falls, transitions to other setting and lacking ACP. Most relatives were satisfied with end-of-life care (open questions and EOLD-SWC). They were dissatisfied with physician's communication, staffing levels and continuity on the ward. Involving volunteers increased satisfaction rates.

Conclusions: ACP discussions are important to symptom management and comfort at the end of life with dementia in the nursing home setting. Most relatives were satisfied with end-of-life care. Staff (nurses and physician, volunteer) engagement is related to this satisfaction.

Abstract number: J-03
Abstract type: Oral

Factors Associated with Emergency Department Attendance by People with Dementia Approaching the End-of-Life: A Systematic Review

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Background: People with dementia often experience repeated health crises, resulting in emergency department (ED) attendance. These attendances can be distressing and detrimental for people with dementia and yet increase as individuals approach the end of life.

Aims: To identify factors associated with ED attendance by people with dementia approaching the end of life.

Methods: Systematic search of six databases (MEDLINE, EMBASE, ASSIA, CINAHL, PsycINFO and Web of Science) and review of grey literature. Extracted data were synthesised using vote counting based on direction of effect. Using a theoretical framework, results were categorised as individual, clinical, or environmental factors. Strength of evidence was determined using a pre-established algorithm.

Results: Of 18,204 references, 367 were selected for full-text review. Findings of 23 studies were synthesised. Eleven factors of at least moderate strength evidence were identified. High strength evidence supported associations between reduced ED attendance and higher socio-economic status, living in a care home and being unmarried. There was also high strength evidence of associations between increased ED attendance and previous hospital transfers, minority ethnic groups, presence of depression, number of comorbidities, and rural living. Moderate strength evidence supported associations between reduced ED attendance and being a woman, having severe cognitive impairment and receiving palliative care.

Conclusions / Discussion: This review has identified key factors associated with ED attendance by people with dementia approaching the end of life. Interventions to enable people to remain in usual residence should target patient groups from ethnic minority backgrounds, rural residence, and those with lower-socio-economic status, depression, comorbidities, and previous hospital transition.

Abstract number: J-09
Abstract type: Oral

Patterns of Unplanned Hospital Admissions among People with Dementia: From Diagnosis to the End of Life

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Background: Unplanned hospital admissions can be burdensome for people with dementia. We do not know how patterns of unplanned hospital admissions change after diagnosis until death.

Objective: To describe the patterns of unplanned hospital admissions of people with dementia from the point of diagnosis.

Methods: Retrospective cohort study using mental healthcare provider database, linked to mortality and hospital data. People aged ⩾ 50 with a recorded dementia diagnosis were included until death or study end. We obtained sociodemographic, admission and illness-related variables. Sample was stratified by duration since first dementia diagnosis. Cumulative incidence, and rates for unplanned hospital admissions were calculated.

Results: Cumulative incidence of unplanned hospital admissions was 76.8% (95% CI 76.3% - 77.3%, n=14,759) for 19,221 people (1995-2018). People who died accounted for 39,070 (72.3%) of 54,017 unplanned hospital admissions (mean per person 3.7 (SD3.7) mean length of stay 8.3 (SD42.7) days). Unplanned hospital admission rates increased in the last year of life and were higher for people diagnosed for a shorter duration; especially in those who died. Overall rates were lower for people diagnosed for longer. Compared to those who were diagnosed for longer, people who were diagnosed for shorter were older when diagnosed, had more comorbidities, behavioural, cognitive and social functioning impairment. Infections were the most common reasons for hospitalisations.

Conclusions: Unplanned hospital admissions increase towards end of life for people with dementia, with higher rates in people diagnosed for a shorter time. Understanding heterogeneity and timing of unplanned hospital admissions may help plan timely care.

Abstract number: L-10
Abstract type: Oral

Developing a Benchmarking Tool for Evaluating the Quality of End-of-Life Care in Care Homes

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Background: Enhancing the quality of end-of-life care in care homes has been among the top government policy agenda globally owing to the increased prevalence of chronic progressive diseases in the older population. However, consensus has yet been reached on how to evaluate relevant care services in an objective manner.
Aims: This study aimed to develop a tool for assessing the quality of end-of-life care services in the care home setting.
Methods: This is a capacity building project adopting a participatory action research approach in government-funded care homes in Hong Kong between 2016 and 2021. A list of quality indicators related to palliative and end-of-life care in care home setting were identified through a scoping review. The list was finalised with 30 indicators regarding policy, staff education, assessment and management of symptoms, care for dying residents, family support and bereavement care, following consultation of 15 local, regional and international experts. Then, the superintendents of the care homes in the project were asked to indicate if their care homes met the requirement for three consecutive years.
Results: Thirty six care homes completed the first 3-year cycle of the project. At baseline, 14 indicators mainly related to advance care planning, documentation and arrangement for dying residents, were not implemented in over half of the care homes. At 1-year follow up, all indicators, except two about care for deceased residents and support for religious practices, were implemented in most of the care homes. Similar patterns were observed at the 2-year follow up.
Discussion: This is the first initiative aiming to enhance the quality of end-of-life care in care home setting in the Chinese communities through a systematic approach. A benchmarking tool was developed based on internationally-recognised standard for identifying service gaps, and thus provide insights into organizational and policy development.

FC 12 Palliative Care Identification and Impact

Abstract number: J-01
Abstract type: Oral

Population-based Projections of Place of Death for Northern Ireland by 2040

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Background: An increasingly older population, with escalating numbers of deaths and increased demand for end-of-life care presents challenges worldwide. It is therefore vital that Health and Social Care examine where people die in order to forward plan.
Aim: Establish where people have died 2004-2018 and project which care settings will require more end-of-life care resources by 2040.
Methods: Population-based trend analysis of place of death in Northern Ireland (2004-2018 from Northern Ireland Statistics and Research Agency). Projections used linear modelling (2019-2040 projections by Office of National Statistics).
Results: Deaths are projected to increase by 45.9%, from 15,922 in 2018 (of which 36.3% will be aged 85+ years) to 23,231 deaths in 2040 (39.8% aged 85+ years). From 2004 to 2018, proportions of home and care home (defined as nursing and residential beds) deaths increased (24.5-27% and 16.3-19.4% respectively), while the proportion of hospital deaths declined (51.9-47.6%). If these trends continue, deaths within the community (home and care home) will account for between 46.7-55.2% of all deaths by 2040. However, if care home capacity is capped at current levels (as of 2018), hospital deaths are projected to account for the largest proportion of deaths by 2040 (51.7%).
Discussion: Rising deaths in an increasingly older population has implications for end-of-life care provision. Findings identified an increasing need for end-of- life care over the next 20-years, particularly within community settings. These projections highlight the need for comprehensive planning to ensure service provision within the community meets population needs.
Funded by Marie Curie.

Abstract number: K-01
Abstract type: Oral

Palliative Care, COVID-19 and Universal Health Coverage: Results of a Global Survey

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Background: The importance of palliative care (PC) in the response to COVID-19 & as a crucial part of essential health services within Universal Health Coverage (UHC) is well recognised. However, despite various policy commitments globally & nationally, there was concern that PC was not being integrated into COVID-19 responses, that essential PC services were being disrupted for adults & children with pre-existing conditions & that people are experiencing avoidable serious health-related suffering (SHS) as a result.
Aims: To understand & highlight the situation in regard to PC access & government integration of PC & UHC during the COVID-19 pandemic.
Methods: An online survey was undertaken of members & partners from three global palliative care networks. The survey was administered through survey monkey & included both closed &open questions. 90 responses were received between 17-29 June 2020 from 40 countries. Quantitative & qualitative analysis was undertaken of the data.
Results: 5 key areas were identified: Access to PC - services for individuals with pre-existing PC needs were disrupted & people with COVID-19 were not getting the PC they need, with vulnerable groups particularly at risk; Government integration of PC - PC was rarely integrated into the COVID-19 response or being financed; Financial sustainability of PC organisations – most are concerned about this; UHC & PC – only 50% reported PC was part of their countries UHC response; & Partnerships for PC – Non PC organisations were supporting the integration of PC into the COVID-19 response.
Conclusion/Discussion: Recommendations have been made to governments to integrate PC into COVID-19 responses, training health workers in PC & build back better through the integration of PC into health systems, including UHC. It is a moral imperative to ensure that adults & children are not experiencing avoidable SHS during the COVID-19 pandemic which could be alleviated through access to integrated & cost-effective PC.

Abstract number: M-03
Abstract type: Oral

Implementation of the Supportive and Palliative Care Indicators Tool (SPICT^{TM}) in General Practice in Germany – An Interventional Study

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Background: Needs of patients in their last phase of life can be adequately met within primary palliative care (PC) provided by general practitioners (GPs). Yet, a structured strategy to identify patients who might benefit from a PC approach is often missing.
Aims: Aim of this study was to implement the Supportive and Palliative Care Indicators Tool (SPICT^{TM}) in general practice in Germany and to evaluate its effects and practicability.
Methods: The study was part of the interventional project "Optimal Care at the End of Life" (OPAL). In 2019, GPs in two counties in Lower Saxony, Germany, received standardised training on applying SPICT^{TM} during regular consultation hours over a period of twelve months in adult patients with at least one chronic progressive disease. A follow-up survey was conducted six months after initial assessment. Data were analysed descriptively.
Results: 43 GPs (n=15 female, median age 53 years) out of 32 general practices applied SPICT^{TM} in daily practice and assessed 580 patients (n=345 female, median age 84 years). Main underlying diseases were of cardiovascular (47%) and oncologic (33%) origin. Follow-up after six months included 412 patients and showed that the most frequently initiated PC actions were a review of current treatment/medication (76%) and a clarification of treatment goals (53%). 217 patients (53%) went through at least one critical incident in the disease progression (e.g. acute crisis) and 141 (34%) had died. The application of SPICT^{TM} was deemed to be practical by 85% of GPs, 66% would like to continue to apply SPICT^{TM} in daily practice.
Conclusion: SPICT^{TM} is a practical tool that supports the identification of patients who are at risk of deterioration or dying and who might benefit from a PC approach. Moreover, the application of SPICT^{TM} supports the initiation of patient-centred measures (e.g. review of medication, clarification of treatment goals).
Funding: Innovation Fund of the Federal Joint Committee (01VSF17028)

Abstract number: M-05
Abstract type: Oral

Concurrent Validity and Prognostic Utility of the Needs Assessment Tool: Progressive Disease - Heart Failure

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Background: People with advanced heart failure have significant supportive and palliative care needs requiring systematic assessment.
Aim: We aimed to assess the validity of the Needs Assessment Tool: Progressive Disease – Heart Failure (NAT:PD-HF) for determining palliative-care needs in a heart failure population.
Methods: Secondary analysis of routinely collected, anonymized patient data from a palliative care-heart disease service improvement pilot. Baseline clinico-demographic information, NAT:PD-HF and the Integrated Palliative care Outcome Scale (IPOS) data were collected. IPOS and patient/carer-report data were repeated at the care-episode end. Analysis: concurrent validity between NAT:PD-HF items and comparison measures (Kendall's tau; kappa); construct validity via known-group comparisons (non-parametric, Bonferroni-corrected tests); predictive utility of NAT:PD-HF for survival (multivariable Cox hazard regression model).
Results: Data from 88 patients (50% men; mean age 85; median survival 205 days; 64% left ventricular systolic dysfunction) were analysed. Persistent symptoms and information needs were the two commonest concerns. Prevalence- and bias-adjusted kappa values indicated moderate agreement for physical symptom needs (k: 0.33 for patients, 0.42 for carers). Substantial agreement was observed for patient/carer psychological symptoms, spiritual and psychosocial, and information needs (k $\geqslant$ 0.6). NAT:PD-HF distinguished between patients with different survival times, number of comorbidities, Australia-modified Karnofsky Performance (AKPS) scores and phase of illness with moderate to high effect sizes. NAT need was not a predictor when adjusted for heart failure mortality risk score and AKPS (2-4 needs HR: 1.58, 95% CI: 0.96-1.83; 5-8 needs HR: 1.54, 95% CI: 0.99 – 1.79).
Conclusions: The NAT:PD-HF is a valid tool for the clinical assessment of physical, psychosocial, information, practical, and family support needs.

FC 13 Advancing Advance Care Planning

Abstract number: I-01
Abstract type: Oral

Evaluating Attitude, Self-efficacy, Behavior, and Intention to Engage in Advance Care Planning Communication in Pediatric Oncology: Development and Face Validation of a New Measurement Instrument

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Background: While structured advance care planning (ACP) has been identified as an important process to improve pediatric cancer care, an appropriate and validated instrument to measure behavior change as a result of ACP communication between adolescents with cancer and their parents, is currently lacking.
Aims: To develop and face-validate an instrument to measure behavior change in adolescents with cancer (age 10-18) and their parents, as a result of ACP.
Methods: The Theory of Planned Behavior instructed identification of four key constructs to operationalize ACP as a health behavior: attitude, self-efficacy, intention and actual behavior. Existing validated ACP/communication-related measures were reviewed (eg PACS, Collaborate Scale, Active Empathic Listening Scale) and combined with self-developed items. The prototype instrument was linguistically improved and made age appropriate by a literacy expert agency. Cognitive interviews with adolescents who were diagnosed with cancer (n=4) and parents (n=6) were then performed. Feedback using thematic analysis and discussions with the researchers informed refinements.
Results: The final instrument includes 7 subscales, each varying between 3 to 20 items. Most are 5-point Likert scale (strongly disagree–strongly agree). Key feedback from testing includes: clarifying clinical jargon and ACP concepts (eg. *"preferences for care and treatment"* changed to *"what is important concerning my care and. . ."*), specifying references to time (eg *"recently"* to *"last month"*) and removal or rephrasal of items perceived as inappropriate (eg items asking about parents' own needs on ACP communication).

Conclusion: We developed and tested an instrument to measure change in different ACP health behavior constructs in adolescents with cancer and their parents. While further validation is needed, it provides an opportunity to select pertinent primary endpoints for intervention studies focusing on parent-adolescent ACP in pediatric oncology.

Abstract number: I-02
Abstract type: Oral

Parental Decision-making Behaviors in Pediatric ACP: A Qualitative Study

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Background: Pediatric advance care planning (pedACP) can help in facilitating goal-concordant care. The pedACP process poses a huge challenge for parents and health care professionals alike, including the need to face prognostic uncertainty.
Aims: We aimed to analyze parental decision-making behaviors during pedACP processes with parents of children with life-limiting diseases lacking decision-making capacity.
Methods: The PREPARE project on pedACP includes a qualitative study employing participatory observation of the conversation processes. Data are analyzed using conversation analysis.
Results: Data analysis shows two broad categories of parental decision-making behavior:

a) decisiveness and certainty: parents are very clear on specific treatment limitations, due e.g. to former decisional regret, experiences of burdensome medical measures, or fear of unwarranted life prolongation;
b) non-decisiveness and ambivalence, leading to reticence towards advance care decisions, due e.g. to fears of making the 'wrong decision', of withholding treatment too early, and worries that health care professionals might 'give up' on the child.

Participatory observation indicates that, especially for less-decisive parents, an open-minded attitude, sensitive communication, interprofessional support and development of anchor criteria are keys to parental trust in pedACP. Relevant anchor criteria observed included 'what is meaningful for the child's life' and carefully negotiated care goals.
Conclusion: To meet parental needs in pedACP we need to understand the different levels of parental decisiveness and to deal with them sensitively. It is crucial to avoid pressuring less-decisive parents on decisions in order not to lose their willingness to engage in pedACP. Developing anchor criteria and negotiating goals of care appear as helpful strategies to prepare for future decisions.
The PREPARE study was funded by the German Federal Ministry of Education and Research [grant number 01GY1709].

Abstract number: I-03
Abstract type: Oral

Patterns in Discussing End-of-Life in Pediatric Advance Care Planning Conversations

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Background: Parents value the opportunity to discuss the end-of-life (EOL) of their seriously ill child in advance. Discussing the EOL is perceived as challenging in clinical practice and is often avoided or postponed. It is unclear how clinicians and parents address the EOL in advance care planning (ACP). Insight in communication patterns can support improvement of EOL communication.
Aim: To assess how clinicians and parents address and respond to EOL themes in ACP conversations
Methods: This study is an exploratory qualitative analysis of 25 ACP conversations based on the Implementing Pediatric Advance Care Planning Toolkit. This toolkit provides prompts to address ACP themes including EOL. Fourteen clinicians, 38 parents and 4 children participated in the ACP conversations. Fragments about the child's EOL were identified and analysed on communication patterns using an inductive qualitative approach.
Results: The child's EOL was addressed in 24 ACP conversations. Clinicians and parents used explicit and implicit questions or statements to initiate a dialogue about the child's EOL. Responses to these initiatives could be direct responses in which the child's EOL was explicitly discussed; indirect responses, that involved talking about EOL in general but not specified for the child's situation; a reflection or paraphrase of the initiative without a subsequent dialogue; or ignoring the initiative by changing to another subject. Explicit initiatives lead to clear and open EOL dialogues, whereas implicit initiatives were mostly followed by an indirect response. None of the explicit initiatives of clinicians were ignored by parents. Clinicians sometimes ignored an explicit initiative from a parent.
Conclusion: The child's EOL was frequently addressed in ACP. Explicit initiatives to discuss the EOL were followed by concrete EOL dialogues. No evasive responses of parents were observed, suggesting the child's EOL can be addressed safely in a structured ACP conversation.

Abstract number: I-04
Abstract type: Oral

Impact of Advance Care Planning in Pediatric Oncology

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Background: Although outcomes for children with cancer have improved greatly, significant suffering remains, especially for children who die from disease. Pediatric Palliative Care (PPC) seeks to lessen this burden, one of the most useful tools being an advance care plan (ACP).
Aim: To evaluate the impact of ACP in the experience of children who died from cancer in a Pediatric Oncology Department (POD).
Methods: Medical records of children who died between 01/15-12/19 from progressive disease were reviewed. Bivariate analysis by ACP status was performed; statistical significance was set at $p < 0.05$.
Results: 113 children were included, 51% male. Age at death ranged from 3 m-18y (<1=3%; 1-5=31%; 6-10=28%; 11-14=23%; 15-18=14%). Most children had solid tumors (46%); 46% had documented ACP. Overall, median time admission-death was 1.4y; to first ACP was 1.8y. Most patients died in a ward (table). Survival was longer in children with ACP (2.0 vs. 0.8y, $p < 0.001$).
Discussion: Despite limitations, our study found that children with an ACP trended towards death at home or a PC unit and none died in ICU. These findings highlight the relevance of ACP in planning place of care/death. Children with an ACP (though many initiated late in the disease course) also had an increase in survival. This may mean better supportive care vs. clinicians being more likely to discuss ACP with patients expected to live longer, warranting further research. PODs should strive to integrate PPC and promote ACP discussions early in the course of disease.

	W/O ACP (N = 61)	W/ACP (N = 52)	p
Age at time of death, y (IQR)	6 (3-11)	10 (6-14)	0.005
Time from admission to death, y (IQR)	0.8 (0.4-2.3)	2.0 (1.2-3.6)	<0.001
Place of death, N(%)			0.001
Home	2 (3)	11 (21)	
Oncology ward	33 (54)	28 (54)	
Other ward	17 (28)	11 (21)	
ICU	9 (15)	0	
PC unit	0	2 (4)	

Abstract number: I-10
Abstract type: Oral

Conceptualising Paediatric Advance Care Planning; Is it More than Just 'Do Not Attempt Resuscitation'?

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Background: Advance care planning is considered part of the standard of care for children with life-limiting conditions worldwide, although there remains inconsistency in approach to this care. Theoretically, it aims to help families and paediatricians prepare and plan for end of life decision making. However, there is a paucity of literature describing what this preparation involves, and whether paediatricians recognise a difference between the process of advance care planning and its potential documentation, such as resuscitation plans.
Aim: To understand how paediatricians conceptualise advance care planning in their care of children with life-limiting conditions.
Methods: Individual semi-structured interviews of 25 purposively sampled paediatricians were conducted between May 2019 and June 2020. These audio-recorded interviews incorporated a clinical vignette relevant to the clinical practice of each paediatrician. Interview transcripts underwent inductive content analysis.
Results: Four key themes were identified; (1) advance care planning as part of the continuum of decision making, (2) the emotional impact of advance care planning, (3) elements of advance care planning discussions, and (4) adopting a family-centred approach. When considering the elements of advance care planning discussions, paediatricians identified three broad steps; (i) communicating the child's potential risk of death, (ii) moving from fantasy to reality, and (iii) documentation of decisions related to resuscitative measures or intensive care technologies.
Conclusion / discussion: The process of advance care planning is often under-recognised and under-valued by paediatricians. Hesitancy in documenting decisions in advance was described. Elements of discussions to prepare families and paediatricians to make decisions at the time when the child is seriously unwell are practiced but not necessarily intentionally or described in terms of advance care planning.

FC 14 Families and Carers

Abstract number: C-02
Abstract type: Oral

Dying at 'Home': Bereaved Family Caregivers' Experiences of Just-in-Case Medications at End of Life

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Background: More than half of patients with a terminal diagnosis wish to die at home. NICE recommends provision of Just-In-Case (JIC) injectable medications as a way of managing symptoms and facilitating this. There is little published evidence however regarding the experience of family caregivers (FCGs) in relation to the presence of these in the home and the administering of these when needed.
Aim: The objective of this study was to explore FCGs' experiences and identify ways to improve practice.
Methods: Thematic analysis of 14 semi-structured interviews, undertaken with 18 FCGs who had JIC medications in the home. These were identified through purposive sampling of FCGs who had completed a questionnaire sent 3 to 9 months post-bereavement.
Results: Some FCGs reported feeling shocked and distressed when they realised that these medications indicated that their relative was approaching end of life. There were also concerns associated with obtaining, storing and eventually disposing of such medications. Administering these medications, particularly in terms of sourcing the right support from professionals in a timely manner often proved problematic. FCGs expressed a willingness to engage with administering JIC medication, but worried about legal and moral implications whilst others felt their emotional involvement might hamper their efforts. Those most likely to become involved in administering were those with some previous health experience or training. A number of systemic barriers also impeded the smooth administering of JIC medications.
Conclusion: Most FCGs find having these medicines generally positive but for some it is a source of distress and anxiety especially where there has been poor communication and professional support has been difficult to access at the point at which it has been needed. A good experience relies heavily on the confidence, competence and continuity of the staff overseeing all aspects of the patient's end of life.

Abstract number: C-04
Abstract type: Oral

Family Carers' Support from Healthcare Professionals in Conducting ACP Conversations with their Seriously Ill Relatives: A Cross-sectional Survey of Bereaved Family Carers

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Background: Family carers' (FC) have a prominent role in caregiving for people with serious illness. No studies, so far, have examined to what extent FC perform ACP conversations with their relative, whether and by which healthcare professional (HCP) they are supported to do these conversations, and in what manner they are supported.
Aim: To investigate what proportion of FC have discussed ACP with persons with a serious chronic illness in the final 3 months of life and to investigate what proportion of these FC received support from HCP for these conversations, how they were supported and whether or not the support received was sufficient.
Method: Population-based cross-sectional survey of bereaved FC of persons with a serious chronic illness (N=3000). The survey asked about whether or not FC had had ACP conversations with their chronically ill relative in the final 3 months of life, whether or not the FC were supported by HCP for these conversations, how and if they evaluated the support as sufficient.

Results: The response rate was 53.3%. The proportion of FC engaged in an ACP conversation with their relative was 46.9% (n=564). Of these, 21.9% indicated they were not supported by any HCP to do ACP conversations. Those who were supported, were so most often (50%) by a general practitioner and most often by doing the ACP conversation together (51%), less often by educating the FC in how to do ACP conversations (18.9%) and rarely by referring to other useful sources on how to do ACP conversations (9.9%). For 63.5% of the FC, the support received by the HCP was deemed sufficient.
Conclusion: Our study is the first to provide a population-based estimate of the proportion of FC that has ACP conversations with their seriously ill relatives, which happen in about half of FC. Our study indicates that HCP involve FC in ACP conversations with seriously ill persons, but a more empowering support aimed at enabling FC to do the ACP conversations themselves is rare.

Abstract number: C-06
Abstract type: Oral

A Systematic Review with Narrative Synthesis on Mutual Support between Patients and Family Caregivers in Palliative Care

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Background: Studies on family caregiving in palliative care have traditionally conceptualised family caregivers as providers of support and patients as recipients of support. Hence, how patients and family caregivers in palliative care support one another is poorly understood.
Aim: To identify how the patient and family caregiver in palliative care act as mutual support for one another.
Methods: A systematic review and narrative synthesis of original studies published between January 2000 and March 2020 pertaining to mutual support between patients and family caregivers in palliative care was conducted. Databases searched included MEDLINE, CINAHL, Embase, AMED, PsycINFO, and PsycARTICLES. Only studies published in full and in English and which reported on the patient and/or family caregiver perspective were included.
Results: Ten studies (three quantitative and seven qualitative) met inclusion criteria. Most studies comprised only cancer patients and/or their family caregivers and were conducted in western developed countries. Synthesis of the studies revealed that patients and family caregivers supported one another by remaining positive for each other, by disclosing their concerns to each other, and by adapting together to their changing roles. However, patients and family caregivers did not routinely communicate their distress to each other, and lack of mutual disclosure resulted in conflict between them. Limited support from the wider family made family caregivers feel challenged in their caregiving role.
Discussion/conclusion: Research on mutually supportive relations between patients and family caregivers in palliative care is limited in scope. Studies to identify more substantively, actions or interactions that explain how patients and family caregivers in palliative care act as mutual support for one another, are needed. The impact of the wider family on supportive relations between patients and family caregivers in palliative care requires close attention.

Abstract number: C-07
Abstract type: Oral

Caregiving Experiences of Informal Carers of People Living with MND; A Qualitative Evidence Synthesis

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Background: Motor neurone disease (MND) is a neurodegenerative disease with rapid progression & potential for complex, disabling symptoms & care needs. Its progression & associated deterioration in health is likely to occur over weeks & months & requirements for care often fall to informal carers. The caring role can impact on carers' quality of life & cause psychological distress. Understanding the experiences & needs of carers is vital so that appropriate support can be provided & that services are configured to reflect their needs.
Aims: To explore the caregiving experiences of informal carers of people living with MND through a qualitative evidence synthesis (QES).
Methods: A QES using the 14 domains from Carers Support Needs Assessment Tool (CSNAT) as an a priori framework for synthesis. Searches in CINAHL, MEDLINE, PsycINFO, & Social Science Citation Index used terms for MND, amyotrophic lateral sclerosis, palliative care, qualitative research. Included papers were data extracted & assessed for quality.
Results: 42 papers were included, representing the experiences of 596 carers. Caring for someone with MND has impact emotionally & physically from the point of diagnosis. Carers frequently place the needs of the individual with MND before themselves, neglecting their health, other family & their careers & struggle to take time away from caring. Carers need to be able to trust individuals & services who offer support in order to take a break. Formal support for people with MND should be given by those skilled in caring for someone with the disease in order to be of value. Carer support interventions should be available outside normal working hours for carers in paid employment/with other commitments. The CSNAT domains provided an effective a priori framework for analysis.
Conclusion: Carers of people with MND have specific support needs throughout the course of the disease & require those providing care to have specialist knowledge in order for it to be effective.

Abstract number: L-05
Abstract type: Oral

How to Provide Grief Support to Caregivers Systematically? The Evaluation of a Grief Support Toolkit for Generalist Healthcare Professionals

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Background: Supporting caregivers before and after the death of patients with life-limiting diseases is essential in palliative care. Bereaved caregivers often indicate to have missed grief support.
Aim: Develop and evaluate a toolkit for generalist care professionals to provide grief support more systematically.
Methods: The toolkit was developed based on literature, expert input and interviews with professionals, family caregivers. It included a step-by-step guide for professionals, information for caregivers, and at institutional level, appointment and education of grief ambassadors. The toolkit was introduced in five nursing homes, three hospitals, and evaluated after 6 months using focus group interviews with a convenience sample of in total 15 doctors, nurses and department managers. Using thematic analysis, facilitators and barriers for providing systematic grief support after introducing the toolkit were identified. In addition, a quantitative pre- and post-test survey among professionals ($n = 36$ completed both; response rate: 6%) was conducted which assessed awareness of grief support needs, satisfaction with grief support practice, knowledge and skills, and grief support provided before and after the introduction of the toolkit.
Results: According to focus group participants, the toolkit provided a practical guide, increased awareness of the importance of grief support and increased feelings of competence. The main barrier for providing

grief support systematically was lack of skills of professionals to talk to family caregivers about approaching death before start of the dying phase. The pre- and post-test survey showed that the toolkit significantly increased knowledge of and skills for grief support before death (t= -2.8, p= .01 and t= -2.7, p= .01 resp.) but there were no significant changes for other outcomes tested.

Conclusion: Our toolkit facilitates providing grief support more systematically.

Table 1. Facilitators and barriers for providing grief support systematically before and after the death of patients with life-limiting diseases in nursing homes and hospitals assessed after the introduction of the grief support toolkit.

Facilitators:
1. Availability of the toolkit, as a practical step-by-step guide for grief support and a way to increase awareness of the importance and feelings of competence.
2. Awareness among health care professionals that the patient is in the palliative phase of disease.
3. Continuous support and facilitation for systematic grief support by department managers.
4. Appointment of bereavement care ambassadors on each ward.

Barriers:
1. Limited communication skills of healthcare professionals to talk to caregivers about the death of their loved one before the start of the dying phase.
2. Lack of knowledge of health care professionals on early palliative care (in contrast to palliative care in the dying phase).
3. Quality palliative care delivery not receiving high priority on the agenda of the care organization.
4. Lack of time, in particular for bereavement care.

Main funding source: Netherlands Organization for Health Research and Development (ZonMw).

FC 15 Sharing Learning from across the Globe

Abstract number: I-07
Abstract type: Oral

What Matters to Children and Families Facing Advanced Cancer? Identification of Priority Outcomes to Improve Paediatric Palliative Care in Turkey and Jordan

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Background: The global incidence of cancer is increasing, and the Middle East is projected to be one of the most impacted regions. Increasing number of people would benefit from palliative care (PC), but access is poor, especially for children. Individuals with advanced cancer need person-centred PC, yet evidence to date has rarely asked children, young people (CYP) and their families what matters to them.

Aim: To identify palliative care symptoms and concerns among children, young people and their families facing advanced cancer in Turkey and Jordan.

Methods: Semi-structured in-depth interviews were conducted in a Turkish University Oncology Hospital and a Jordanian Cancer Centre. Purposive sampling was used. We recruited 25 CYP with advanced cancer (age 5-17); 15 parents or caregivers of CYP of any age living with advanced cancer; and 12 multi-professional paediatric PC staff. An interdisciplinary and collaborative approach to thematic analysis using NVivo 12 was conducted concurrently across the three partner sites.

Results: 104 interviews were conducted in Turkey and Jordan. Preliminary findings highlight that the main concerns of CYP and their families cover the existing WHO dimensions of PC. Pain was the most reported physical symptom, and fear of the pain caused by needles was one of the most important concerns for CYP. Participants reported that psychological needs were the most important for them, despite not being the priority for care teams. The isolation and limitations to conduct enjoyable activities, CYP's "boredom" during the hospital stay, and fear of infection were among the most reported psychosocial concerns. Staff acknowledged the difficulties in addressing these needs as parents and CYP's needs and expectations were different.

Conclusion: Our data suggest the importance of understanding the children's psychological concerns and addressing their pain. These data will now form a measurement and quality improvement programme in Turkey and Jordan.

Abstract number: I-08
Abstract type: Oral

End of Life Care for Newborns with Major Congenital Malformations in a Tertiary Neonatal Referral Center in Brazil

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Background: Major congenital anomalies (MCA) are an important cause of death in the Neonatal Intensive Care Unit (NICU) and End of life Care of those patients is poorly described.

Aims: To describe end of life care for those patients admitted ina a NICU.

Methods: All newborns with MCA who died during hospitalization in the NICU in a 3-years period were included. Treatment offered up to 48 hours before death, such as ventilatory support (VS), use of vasoactive drugs (VAD), antibiotics (ATB), sedation and / or analgesia, presence of central venous access (CVA), invasive procedures were analyzed as shared decision to limit therapeutic intervention (LTI) and the influence of follow-up by the perinatal palliative care (PPC) group before birth.

Results: 74 newborns with MCA died in the NICU during the study. 81.1% had CVA, 74.3% were on VS, 56.8% received ATB and 43.2% used some sedative or analgesic drugs. 46% of the families chose LTI. 41.9% of families had been followed up by the PPC group during pregnancy. When compared, the group that decided on the LTI and the group on full care, it was observed that there was less exposure to VAD ($p = 0.003$), ATB ($p = 0.003$) and less invasive procedures were performed ($p = 0.046$). There was no change in the VS offered ($p = 0.66$) and palliative extubation was not performed in any patient. The PPC group had a shorter hospital stay ($p = 0.049$), was less submitted to invasive ventilation(IV) ($p = 0.0391$) and received less ATB ($p = 0.018$).

Conclusions: EoL care analyzed at the NICU was characterized by the presence of CVA (81.1%), use of IV (74.3%), use of VAD (70.3%). LTI was characterized by the maintenance of the current treatment at the moment of identification of a terminal situation with rejection of new interventions that could increase suffering. Follow-up by the PPC group allowed the patients' hospital stay to be shorter and that they were less exposed to IV and ATB.

Abstract number: I-09
Abstract type: Oral

The Butterfly Pathway: Supporting Families Following the Antenatal Diagnosis of a Life-limiting Condition in a Neonatal Intensive Care Unit Setting

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Background: Perinatal palliative care pathways are highlighted as tools to improve care and achieve consistency for families facing a life-limiting diagnosis. There are inherent diagnostic and prognostic uncertainties associated with such conditions.This multidisciplinary service, known as the "Butterfly Pathway", is led by a consultant neonatologist in collaboration with the perinatal palliative care team from a children's hospice, fetal medicine team and regional specialists.The main aims of this service are to support families in decision-making about their babies' care and offer comprehensive family support.
Aims: To study the demographic and clinical profile of babies referred antenatally to the service and understand clinical outcomes.
Method: Retrospective review of all babies referred to the pathway (Aug 2016 -Dec 2020). Data were obtained from electronic and paper medical records for mother and baby.
Results: 52 referrals were accepted within the stated time period. The most common reasons for referral were structural, chromosomal and musculoskeletal abnormalities. 92% women agreed to the referral and were seen in clinic. Of the 40 patients seen, a limitation or avoidance of invasive treatment was agreed in 88% cases. Planned interventions at delivery were agreed based on the clinical situation and parents' wishes. Of the 52 patients referred, almost half (24) had an intrauterine death. 26 babies were born alive (50%), of which 11 died within 24 hours of birth.12 babies (23%) were discharged from hospital alive. This comprehensive service provides the opportunity for parents to advocate for their babies and make valuable memories.

Conclusion: PPC pathways have the potential to ensure that families receive consistent, high quality care during a potentially devastating time. This study adds to the evidence that PPC services are usually welcomed by parents, aid decision-making and help support professionals to avoid distressing invasive interventions.

Abstract number: I-12
Abstract type: Oral

Existential and Spiritual Care Needs of Parents of Children with a Life-limiting Condition, a Qualitative Interview Study

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Background: The life-limiting condition of a child affects the lives of parents on many levels. Parents care for their child, often at a cost of professional, social and family life, and have to anticipate the potential prospect of losing their child. Studies indicate that many parents do not feel properly supported when dealing with existential questions that may rise.
Aim: The aim of this study is to explore existential and spiritual care needs of parents of children with life-limiting conditions.
Methods: In this exploratory qualitative study, we held in-depth interviews with parents of children (0-21y) with life-limiting conditions and recently bereaved parents. A thematic analysis was performed by a multidisciplinary team.
Results: 22 parents of 20 children participated. Major care needs relate to reevaluating life goals and expectations, the importance of being present, loneliness and loss of control. Parents describe these themes in an overlapping tension between holding on to normality (even if this is unattainable) and facing the overwhelming seriousness of the illness. They have to continuously adjust their identity to a changing reality. Parents describe positive sides as well, as caring for their child gives them purpose and meaning in life. After the death of a child, next to the grief of losing their child, parents have to 'reinvent' themselves, their family life and social lives.
Conclusion/discussion: Existential and spiritual care needs are not often addressed. By understanding what parents go through, professional care givers may be able to support them better in the future. The challenges of parents relate to how they can reconnect with what makes them human, despite the changes they face in their lives. Normalising conversations on such themes can help parents to feel supported in the loneliness of dealing with existential challenges.
This study is supported by the Dutch Organisation for Health Research&Development (grant no. 10050011910008)

Abstract number: I-15
Abstract type: Oral

Existential Concerns of Children and Young People with Life-limiting or Life-threatening Conditions

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Background: Whilst evidence suggests that children and young people (CYP) with life-limiting or life-threatening conditions (LLLTC) have existential concerns, it is a research area often unexplored, partly due to ethical challenges. Existential concerns can be more difficult for health and social care professionals to elicit in comparison to physical, psychological, or social concerns.
Aim: To explore how CYP with LLLTC conceptualise and express existential concerns.
Methods: Semi-structured qualitative interviews with purposively sampled CYP with LLLTC (aged 5-17) from 9 UK inpatient and outpatient sites. Verbatim transcripts were analysed using framework approach, using inductive and deductive coding in NVivo.
Results: 26 CYP with a range of LLLTC (6 cancer/20 non-cancer) were interviewed. Themes included: uncertainty of the future, determination to live life to the fullest, and meaning of life. CYP often faced uncertainty due to the unpredictability of their LLLTC. They faced internal conflict over accepting the possibility or actuality of death whilst simultaneously wanting to fight to keep going and survive. Being able to live life to the fullest by taking part in activities they enjoy was very important and made life meaningful. Concerns around uncertainty and unpredictability were more commonly described by CYP with cancer, gastrointestinal, congenital, or metabolic conditions than those with neurological or respiratory conditions.
Conclusion / Discussion: Addressing existential concerns is essential for a CYP-centred approach to paediatric palliative care. Despite the challenging topic, this research has identified several existential concerns of CYP with LLLTC. Assessment, management, and care planning must involve and enable CYP to identify goals and concerns most important to them. Working with CYP to set achievable goals for the future offers one way to support a meaningful life.
Funding: EU Horizon 2020

FC 16 Palliative Care and COVID - Session 2

Abstract number: O-02
Abstract type: Oral

The Support Needs and Experiences of People Bereaved in the UK during the Covid-19 Pandemic: Baseline Results from a Mixed-methods Longitudinal Survey

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Background: COVID-19 presents a mass bereavement event, causing over 120,000 deaths in the UK. Unprecedented infection control restrictions also mean that all people bereaved at this time experience high level disruption to end of life, mourning, grief and coping experiences. This study aims to investigate the grief experiences, support needs and use of bereavement support by people bereaved during the pandemic.

Methods: A mixed method online survey of adults bereaved in UK since March 2020, disseminated via media, social media, national associations and community and charitable organisations. Grief was measured using the Adult Attitude to Grief Scale.

Results: Interim findings from the first 532 participants are reported (full baseline results available by time of conference).46% of deaths were confirmed/suspected COVID-19 and 55% of deaths were in hospital. Over half of participants demonstrated ‘severe’ (28%) or ‘high’ (24%) levels of vulnerability in grief, as well as high/fairly high needs for support in six psycho-emotional domains (51- 62%). 21% of those with ‘severe’ vulnerability were accessing individual counselling support, compared with 23% overall. 59% of respondents had not tried to access support from bereavement services; of those who tried, 56% experienced difficulties. Barriers included long waiting lists, feeling uncomfortable asking for help, and lack of appropriate support/knowledge of how to access help. 41% also experienced difficulties getting support from family and friends, reporting issues such as a lack of understanding and struggling without in-person contact.

Conclusions: Results suggest unmet needs for support and problems getting support from friends/family and bereavement services. We recommend increased public information about bereavement support options, increased provision of and investment in bereavement services and flexible ‘support bubble’ arrangements for those bereaved during ‘lockdown’ conditions.

Abstract number: R-10
Abstract type: Oral

Bereaved Relatives’ Quality of Life Pre- and post-COVID-19 Pandemic: Results of the Prospective, Multicenter, Observational eQuiPe Study

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Background: The death of a loved one is considered as one of the most stressful life events. During the COVID-19 pandemic, grief processes are potentially affected due to measures such as social distancing and self-quarantine. This can result in lack of practical and emotional support and intensify feelings of loneliness. Personal self-care can be hindered by COVID-19 since social activities are cancelled and contact with friends and family is limited.

Aims: The aim of this study was to give insight in the impact of the COVID-19 pandemic on the experienced quality of life (QoL), social support, and self-care of bereaved relatives in order to evaluate whether care for bereaved relatives during the COVID-19 pandemic should be improved.

Methods: A cross-sectional analysis using data of bereaved relatives of a prospective, longitudinal, multicenter, observational study on quality of care and QoL of patients with advanced cancer and their (bereaved) relatives (eQuiPe). QoL (EORTC QLQ-C30), social support (FACT-G) and self-care (SCPS) of bereaved relatives who completed a questionnaire within 3-6 months after their loved one died, during the COVID-19 pandemic (April-November 2020) were compared with bereaved relatives who completed this questionnaire pre-COVID-19 (April-November 2019).

Results: 91 bereaved relatives were included in the analysis, 44 bereaved relatives completed the questionnaire pre-COVID-19 pandemic and 47 post-COVID-19 pandemic. The median age of the participants was 65 (IQR=14) years and 58% was female. There were no significant differences between the pre-COVID-19 and the post-COVID-19 bereaved relatives in QoL (68 vs 69), emotional functioning (72 vs 71), social functioning (82 vs 82), self-care (20 vs 19) and social support (17 vs 18).

Conclusion / Discussion: On the short-term, the COVID-19 pandemic does not have significant impact on bereaved relatives’ wellbeing. However, long-term impact of the pandemic on their wellbeing should be assessed.

Abstract number: R-12
Abstract type: Oral

How the COVID-19 Pandemic Affects Palliative Care Inpatients and Outpatients without a COVID-19 Diagnosis and Their Families - A Qualitative Interview Study

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Background: During humanitarian crises like a pandemic, healthcare systems worldwide face unknown challenges. It is likely that the COVID-19 pandemic (C-pandemic) affects care structures and processes in palliative care and thus the patients cared for. Little is known about the situation of non-COVID-19 palliative patients during the pandemic.

Aim: The study aims to explore and describe the effect of the current C-pandemic on the needs of patients without a COVID-19 diagnosis and their relatives in palliative care units and specialist palliative home care.

Methods: Qualitative, semi-structured interviews with patients and their relatives in palliative care units or specialist palliative home care, verbatim transcription, and qualitative content analysis following the framework approach. The framework is developed inductively.

Results: 31 interviews were conducted with patients/relatives (16/15) in palliative care units/specialist palliative home care (20/11) from June 2020-January 2021. Identified needs are mostly independent of the C-pandemic and correspond to those arising from a palliative life situation in general. Themes related to the C-pandemic were (1) concerns about an infection, (2) concerns about the overall social situation, and (3) effects of the pandemic on general care. We identified a change in the relatives’ role as caregivers: Restriction on visits limit relatives to fulfill their role in palliative care units. In specialist palliative home care, relatives are concerned about the balance between preserving social contacts at the end of life and preventing infection by reducing social contacts.

Conclusion: Needs at the end of life remain identical in the context of the C-pandemic but become more multifaceted as additional C-pandemic needs emerge. With regard to the C-pandemic special attention should be given to the needs of relatives as caregivers.

Abstract number: R-14
Abstract type: Oral

Death and Bereavement due to COVID-19: A Discourse Analysis of Online Newspapers with Implications for End of Life Care

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Background: The COVID-19 pandemic has been followed intensely by global media. News media create a sense-making narrative, shaping, reflecting and enforcing cultural ideas and experiences. We aimed to explore British newspaper reportage of COVID-related death and bereavement and consider clinical implications.
Methods: Discourse analysis of the 7 most-read online UK newspaper articles published during two week-long periods in March-April 2020. 55 articles discussed bereavement after a human death from COVID-19. Analysis was informed by Terror Management Theory, which describes a psychological conflict arising between the realisation that death is inevitable and largely unpredictable and the human need for self-preservation.
Results: We identified 3 main narratives: (1) fear of an uncontrollable, unknown new virus and its consequences; (2) managing uncertainty and fear via prediction of the future and calls for behaviour change; and (3) mourning and loss narratives. Within these narratives, the act of 'saying goodbye' (before, during and after death) was central, represented as inherently important and profoundly disrupted. Bedside access was portrayed as restricted, variable and uncertain, with families begging or bargaining for contact. Video-link goodbyes were described with ambivalence, and patients as 'dying alone' regardless of clinician presence. Funerals were portrayed as travesties and grieving alone as unnatural. Articles focused on what was forbidden and offered little practical guidance about what to do if a loved one became seriously ill or died.
Conclusion: Reporting reflected the tension between focusing on existential threat and the need to retreat from or attempt to control that threat. Measures to mitigate the impact of COVID-19 on 'saying goodbye' were presented as insufficient attempts to ameliorate tragic situations. More nuanced and supportive reporting is recommended. Clinicians play an important role in offering alternative narratives.

Abstract number: R-15
Abstract type: Oral

"I Promised my Husband I Wouldn't Leave him Alone": Burdens due to Visit Restrictions for Dying Patients during the COVID-19 Pandemic in Germany: A Mixed-methods Study of Bereaved Relatives

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Background: For infection control reasons, dying patients in care facilities were isolated from their relatives due to visit restrictions, regardless of COVID-19 diagnosis.
Aim: To explore bereaved relatives' experiences with visit restrictions of dying patients during the COVID-19 pandemic.
Methods: Post-bereavement online survey plus additional semi-structured in-depth interviews to assess relatives' experiences with patients who died between 3.-11.2020 in different care settings, with/without COVID-19. Quantitative data were analysed descriptively including subgroup analysis and qualitative data by content analysis. The presented results focus on relatives' experiences with visit restrictions and are part of the PallPan project which develops a "National Strategy for Palliative Care during a Pandemic". PallPan is a project of the National Network University Medicine (NUM) to manage and overcome the pandemic.
Results: 81 relatives responded to the online survey, 87.5% felt burdened by the pandemic-associated circumstances, 9.6% reported that even after the end of the official visitor ban, visits were not allowed in all facilities and the majority of relatives (65.4%) still felt burdened. Interviews with 32 relatives revealed the importance of visits respectively the burden relatives suffered when visits were prohibited. This caused difficulties in communication with the healthcare team about the patient's condition/treatment and reduced the possibility of (physical) closeness with the dying. Case-by-case decisions to allow companionship and farewell were valued by the bereaved.
Conclusion: Visit restriction at the patient's end of life caused a great burden on relatives even months after the patient's death. Concepts to enable visits during the last days of life are needed including flexible pathways to ensure shared time and close companionship of patients and relatives.
Funding: German Federal Ministry of Education and Research; No. 01KX2021.

Thematic Tracks

A	**Innovation & New Technologies**
B	**Pain & Symptom Management**
C	**Informal & Formal Caregivers**
D	**Older People**
E	**Education & Advocacy**
F	**Ethics, Policy and Law**
G	**Disadvantaged Populations**
H	**Psychological, Social & Spiritual care**
I	**Paediatric Palliative Care**
J	**Public Health & Epidemiology**
K	**Policy, including International Developments**
L	**Development and Organisation of Services**
M	**Primary and Integrated Care**
N	**Communication**
O	**Bereavement**
P	**Volunteering**
Q	**Research Methodology and Methods**
R	**COVID 19**

A Posters Innovation and New Technologies

Abstract number: A-01
Abstract type: Poster

Self-management of Persons with Advanced Cancer and their Relatives: The Pilot Study of the Online "Living with Cancer" Programme

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Background: There are few evidence-based programmes available that support patients with advanced cancer and their relatives in their self-management. We developed a novel version of the face-to-face Cancer

Thriving and Surviving self-management programme, called the "Living with Cancer" programme. Novel elements are

(1) target group of patients with advanced cancer;
(2) including patient's relatives; and
(3) a digital format.

The programme consisted of six peer-led video group meetings of one hour, including learning self-management skills (e.g. action planning) and discussing themes (e.g. uncertainty and pain).

Aim: To assess the feasibility of a peer-led, video-based self-management support programme for patients with advanced cancer and their relatives.

Methods: A pilot study with one group to evaluate the programme and its logistics was conducted. Participants were recruited through healthcare professionals and social media, and informed consent was given. Participants filled in a diary of their weekly self-management behaviours, and an online questionnaire afterwards. In-depth interviews with all participants about experiences, and the meeting recordings were evaluated.

Results: Seven patients, 3 relatives and 2 possible future peer volunteers participated. Nine participants completed all meetings, 3 missed one or two. Participants evaluated the digital format as acceptable. All themes that were discussed were considered important and were recommended to be included in the final programme. Patients and relatives participating in the same group were positively appraised. The mean score for satisfaction was 8.5 (scale 0-10). Participants advised longer meetings (1,5 hours).

Conclusion: This pilot shows the feasibility of the "Living with Cancer" programme. Study of its effectiveness will start mid-2021 and will give insight into the value and potential of digital, peer-led self-management support in this population.

Funding: Dutch Research Council (NWO, VIDI)

Abstract number: A-03
Abstract type: Poster

Do Patients with Advanced Cancer Use Telehealth Approaches? A Systematic Review of Digital Engagement across the International Literature

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Background: Telehealth approaches are increasingly being used to support patients with advanced diseases including cancer. Evidence suggests telehealth is acceptable to most patients, however, the extent of and factors influencing patient engagement remain unclear.

Aim: To characterise levels of digital engagement (DE) in people with advanced cancer with telehealth interventions.

Methods: A comprehensive search of databases was undertaken for telehealth interventions (communication between a patient with advanced cancer and their health professional via digital technologies) including MEDLINE, EMBASE, CINAHL, PsycINFO, and Web of Science, up until 2020. A narrative synthesis was conducted to outline the design, population, and context of studies. A conceptual framework comprising behavioural measures (frequency, amount, duration, and depth of use) framed analysis of DE. Frequency data were transformed to a percentage (actual engagement as a proportion of intended engagement), and interventions were characterised by intensity (high, medium and low intended engagement) and mode of delivery for standardised comparisons across studies.

Results: Of the 15,741 identified papers, 35 papers, covering 34 different studies, were eligible for inclusion, dominated by US studies (n=20). A standardised percentage of actual engagement was derived from 16 studies (n=1,628), ranging from 51% to 100%, with a weighted average of 77.6%. A directly proportional relationship was found between intervention intensity and actual engagement. Higher engagement occurred with younger samples and where a tablet computer or smartphone application was the mode of delivery.

Discussion: Understanding DE for people with advanced cancer can guide the development of telehealth approaches from their design to monitoring as part of routine care. With increasing telehealth use, research is needed to define and develop meaningful, context- and condition-appropriate measures of DE for palliative care.

Abstract number: A-05
Abstract type: Poster

Perceptions of an eHealth Palliative Care Intervention for Cancer Patients Leveraging Patient Reported Outcomes: A Qualitative Study of Health Providers, Adult Patients, Children and Parents

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Background: Improving patients' quality of life requires assessment and treatment of psychosocial, physical and spiritual problems.

Aims: To elicit perceptions of healthare professionals (HCPs), adult patients and children with their parents, concerning an ePRO based palliative care intervention for cancer patients.

Methods: This was a cross-sectional, qualitative study designed to assess the acceptability of the MyPal intervention: an eHealth platform for patient reported outcomes (ePROs). Patients are empowered to capture and communicate their symptoms to their HCPs via a mobile app and a serious game.

10 focus groups (4-8 participants) were conducted in Greece, Italy, Germany and the Czech Republic, with:

a) adults diagnosed with hematological malignancies,
b) HCPs,
c) children with hematological or solid cancers and their parents.

Three versions of vignettes were prepared for different groups illustrating the use of the mobile app and serious game involving characters in realistic situations. Using a participatory design process, aspects of the intervention were discussed to elicit participants' perceptions. Thematic analysis was employed for data analysis.

Results: The majority of participants appreciated ePROs, for reporting physical and psychological symptoms, complementing clinical information, allowing direct contact with HCPs, and enhancing self-monitoring. However, adult patients had concerns about privacy, transfer and interpretation of collected data. Parents voiced concerns about the game's suitability for different age groups. HCPs worried about the timeframe within which a response to patients' symptoms would be required. Reported concerns led to modifications to the eHealth Platform design.
Conclusions: Participants' positive judgements validate the development of ePRO based palliative care interventions, however evoked concerns should be taken into account in the design phase.

Abstract number: A-08
Abstract type: Poster

A Systematic Review of Interactive Web-based Tools to Support the General Population in Advance Care Planning

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Background: With the growing use of the internet, more web-based advance care planning (ACP) support tools (i.e. online aids in any format) are becoming publicly available. While these tools can increase the accessibility of ACP, their quality might vary substantially. Currently, there is no comprehensive overview of these tools, their characteristics and quality.
Aims: To describe the format, aim, and development process of web-based ACP support tools and evaluate the quality of their content.
Methods: A systematic review of web-based ACP support tools in online grey literature using the following eligibility criteria: online, designed for the general population, accessible for everyone, interactive (encourage to reflect, communicate and/or document) and in English or Dutch. We evaluated the quality of the content of the tools using the validated *QUEST Tool* resulting in a quality score between 0-28 (higher score is a better quality).
Results: Thirty tools met the eligibility criteria: 15 websites, 10 online portals, 2 apps, and 3 with a combination of these formats. Most tools (n=24) mentioned a clear aim: to support reflection and/or communication (n=7), to support people in making decisions (n=8) or to document decisions (n=7) and 2 aimed to achieve all these aims. Seven tools provided information on the development: all were developed in collaboration with healthcare professionals and three also with end-users. The quality scores of the tools ranged between 11 and 28, with most of the lower scoring tools not referring to scientific information or providing biased information.
Conclusion: There are a wide variety of ACP support tools for the general population available online in terms of their characteristics and quality. Only three tools included end-users in the development, even though this is highly recommended in literature on developing new technologies.
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Abstract number: A-10
Abstract type: Poster

Healthcare Technologies in Long-term Care Facilities for People with Dementia in The Netherlands

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Background: The use of healthcare technology in long-term care facilities for people with dementia is a relatively new and promising development. Healthcare technology can support care staff and improve the quality care.
Aims: To provide an overview of

(1) different types of healthcare technologies used within long-term care facilities for people with dementia, including their purposes, and
(2) bottlenecks experienced by care staff and managers considering the application of these technologies.

Methods: Data were collected among 58 long-term care facilities which participated in the fifth round of the Dutch Living Arrangements for people with Dementia (LAD)-study. Care staff (n=588) and supervisors (n=58) completed an online questionnaire which included questions about the use of and experiences with healthcare technologies. Managers (n=58) were interviewed. We performed quantitative and qualitative analysis.
Results: All long-term care facilities used healthcare technologies, on average eight different types per facility. Most commonly used technologies are motion detection in bedrooms and digital communication systems for care staff. Promoting safety and autonomy of residents seemed to be important goals of healthcare technologies, whereas support of care staff was not reported. Managers indicated high costs, environmental factors and a lack of ownership as major bottlenecks to successful application of technologies. Care staff mentioned a lack of stability, training and user-friendliness.
Discussion: The application of different types of healthcare technologies seems common among Dutch long-term care facilities for people with dementia. According to our study, the ultimate goal of technologies is promoting the well-being of the resident. For a successful implementation of technologies, sufficient and appropriate training for care staff should be provided to make sure that everyone knows how healthcare technologies work and can be used and applied optimally.

Abstract number: A-11
Abstract type: Poster

Radar-based Monitoring of Movements for Objective Assessment of Health Status: A Proof-of-Technological-concept Study for Palliative Care Application

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Background: In health care everyday movements and their changes (frequency, precision) over time may serve as biomarkers for health status. The most common method to assess these is patient observation. However, observation as a method is prone to distortion by subjectivity and unrepresentative snapshots.
Aims: Proof-of-concept that touchless and continuous radar-based sensors allow for monitoring and classification of target movements.
Methods: Four different exemplary patient movements a) picking up a cup, b) reaching for medical trapeze, c) touching head, d) touching stomach (c and d models of involuntary movement suggesting pain) were determined. In a simulated clinical set up (bed, table and

medical trapeze) 5 healthy volunteers performed movements a-d in 5 repetitions, resulting in a dataset of n=100 movements. Two radars (77GHz FMCW, beside and in front of participant, distance by chirp-sequence modulation) and optical motion sensors (OMS, goldstandard-validation) recorded the movements. Radar and OMS recorded speed and distance relative to radar-position. A MATLAB-based algorithm classified movements following an a) vs. b) vs. c)/d) system.
Results:

- Radar-system detected movements a), b), c), and d)
- Movement-profiles (determined by absolute and relative maxima and minima of velocity and distance) correlate between radar and OMS
- Based on this, an algorithm discerned correctly a) from b) from c)/d) in 60 of 60 random sample cases

Conclusion: This proof-of-technological-concept study shows that radar-based sensors can monitor movements as possible biomarkers for state of health. The role of movements as biomarkers for health status has to be further elaborated. Radar based monitoring may help due to the objectivity of the assessment. As it is touchless and burden-free this technology can become instrumental in vulnerable patients, as in palliative and end of life care.

Abstract number: A-12
Abstract type: Poster

Walkthrough Digital Virtual Hospice Tour: A Survey Study to Explore practicality and Acceptability for Patients

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Background: Patients referred to a hospice may feel trepidation about this unknown environment, and the word hospice can carry stigma for some. Virtual Reality (VR) applications allow users to feel present and become immersed in a realistic computer-generated environment and are used for instance by estate agents for house viewings. Our cancer hospital in Cardiff uses 360◦ photo/video technology on tablet computers to give patients a 'digital tour' of two regional hospices.
Aims: To evaluate whether the use of these 360◦ walkthrough tours of local hospices is acceptable to patients/proxy and readily implementable within a clinical environment.
Methods: 360◦ filming/photography was undertaken in two local hospices & uploaded to hospital media pads. An online survey was created to assess patients'/relatives' experience. Patients on the ward for whom a hospice referral was suggested by the MDT were offered this digital tour and were included in this survey. Staff were asked whether it was easy to use.
Results: Of 25 patients/relatives, 90% felt the 360◦ tour improved their readiness for hospice transfer. Also, 95% of patients/relatives stated they would recommend it to other patients being referred to hospices. All patients/proxy found it acceptable. Staff felt the 360◦ tour was easily integrated into their work, and preferred using tablet computers over VR headsets.
Conclusion: The technological use of 360◦ hospice photographic views as an introduction to the hospice infrastructure can make a difference to patients/proxy and addresses the fear of an unknown environment. Integration of this innovative technology into the clinical environment is feasible and appears acceptable to patients. Creating 360◦ imagery in local hospices was not technologically difficult, but is aided by availability of staff interested in digital media. Furthermore, informal hospice visits were curtailed during the Covid-19 pandemic, driving up the usage of these virtual tours significantly.

Abstract number: A-13
Abstract type: Poster

A Novel Palliative Care Telemedicine Service in a Tertiary Cancer Institute: What Are Factors Associated with Uptake of this Service? A Preliminary Update

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Background: Providing outpatient palliative care services is difficult in the COVID-19 pandemic due to resource constrains. We piloted a novel nurse-led telemedicine program from 1st June 2020, to allow patients continued timely access to palliative care services.
Aim: The aim of this study was to understand demographic factors associated with acceptance of a palliative care telemedicine service.
Methods: Inclusion criteria for enrolment of patients in telemedicine were advanced gastrointestinal or lung cancer and prognosis of less than 2 years. Patients known to existing palliative care services were excluded. The telemedicine program consisted of a tele-consult with a palliative care consultant and nurse upon enrolment, followed by weekly symptom monitoring through a patient self-reported survey (Integrated Palliative Care Outcome Scale survey, IPOS) for 12 weeks. Identified problems from IPOS are followed up and managed by the nurse. The demographics of patients who accepted versus those who rejected telemedicine were compared using descriptive statistics.
Results: Out of 55 referred patients, 62% of them accepted the telemedicine service. The median age of patients who accepted the service was younger (66 years) than those who rejected the service (70 years). A higher proportion of males accepted the service (71%) as compared to females (52%). Race did not impact acceptance of telemedicine. Acceptance tended to be lower for patients who stayed in the Southern region near to hospital (43%) as compared to those who stayed in the Western region, far from hospital (83%). Participants who accepted the telemedicine service were more often paying patients (83%) as compared to subsidized patients (56%). Acceptance rate was highest in married patients (69%) as compared to widowed patients (25%).
Conclusion: Our results suggest that socio-economic status, marital status and place of residence impact acceptance rate of telemedicine palliative care services.

Abstract number: A-14
Abstract type: Poster

Virtual Models of Care for People with Palliative Care Needs who Live at Home: A Systematic Meta-review and Narrative Synthesis

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Background: Access to palliative care in the community enables people to live in their preferred place of care, which is often home. Community palliative care services struggle to provide timely 24-hour services to patients and family. This has resulted in calls for 'accessible and flexible' models of care that are 'responsive' to peoples' changing palliative care needs. Digital health technologies provide opportunities to meet these requirements 24-hours a day.
Aim: To identify digital health technologies that have been evaluated for supporting timely assessment and management of people living at

home with palliative care needs and/or their carer(s), and the evidence-base for each.

Methods: A systematic review of systematic reviews ('meta-review'). Systematic reviews evaluating evidence for virtual models of palliative or end-of-life care using one or more digital health technologies were included. Systematic reviews were evaluated using the Risk of Bias Tool for Systematic Reviews. A narrative approach was used to synthesise results. Medline, Embase, Web of Science, CINAHL and Cochrane Database of systematic reviews were searched for English-language reviews published since 2015.

Results: The search yielded 2,266 articles, of which 12 reviews met criteria. Sixteen reviews were included in total, after four reviews were found via handsearching. Other than scheduled telehealth, video-conferencing, or after-hours telephone support, little evidence was found for digital health technologies used to deliver virtual models of palliative care.

Conclusions: There are opportunities to test new models of virtual care, beyond telehealth and/or video conferencing, such as 24-hour command centres, rapid response teams and teleporting.

Abstract number: A-15
Abstract type: Poster

The NASSS Framework to Assess and Reduce Complexity in e-health App Implementation: Development, Validation and Application of the Dutch Version and its Application in Palliative Care

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Objectives: The growing demand of palliative care calls for innovative initiatives. While e-health applications are often considered the holy grail, their implementation often fails. This mostly because technologies are either not adopted or soon abandoned; or fail to scale up, spread to other settings, or be sustained over time (abbreviated as NASSS). The UK NASSS framework is rooted in the idea that e-health applications are more likely to succeed when their level of complexity is reduced in six domains: illness, technology, value proposition, intended adopters, organization(s), and external context. A NASSS toolkit allows measurement of complexity in these domains and provides support to reduce complexity. The objective of this study is to validate the NASSS framework for the Dutch healthcare system and to apply it to palliative care e-health applications.

Methods: We will validate and apply the NASSS framework for use in the Netherlands. After translation and content validation to the Dutch context, we conduct case studies by applying the framework to palliative care e-health applications. The first casestudy is an evaluation of the online Advance Care Planning tool on "thuisarts.nl" (Dutch for "home-doctor"). To understand the barriers and facilitators to successful spread and sustainability, we will analyse existing quantitative and qualitative data (including publications, a SROI analysis, user data, and developer notes), supplemented with stakeholder interviews.

Conclusion: Evaluation of the potential of e-health applications in palliative care is essential in different stages (idea, execution, evaluation) of their development. The NASSS framework can provide a balanced consideration of the level of complexity, which helps researchers, policy-makers and technology developers recognizing how applications can be successfully scaled up, spread and sustained.

Funding: This research is funded by the Netherlands Organization for Health Research and Development.

Abstract number: A-16
Abstract type: Poster

Educating Nursing Home Staff on End of Life Conversations during Covid-19: A Virtual Train-the-Trainer Approach

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Background: End of life conversations can be difficult for both family carers and nursing home staff and can result in "missed conversations" regarding resident's disease progression and health status. During COVID-19, communication between family carers and nursing home staff has proven particularly difficult. Ensuring nursing home staff are educated in how to hold conversations on end of life (EoL) is essential.

Aim: To educate nursing home staff to hold EoL conversations during a pandemic using the virtual learning environment CANVAS.

Methods: Using a Train the Trainer approach an online training course was developed using Fleming's VARK model. This provided resources for an external facilitator to support nursing home staff in holding EoL conversations with family carers virtually. Using the Comfort Care Booklet, modules included strategies to support nursing home staff in communication, good practice and handling challenging situations. Training was provided for external facilitators across six countries who would then support nursing home staff virtually on holding conversations in a virtual environment. Training statistics and anonymised evaluation data were captured by the CANVAS platform.

Results: Twelve facilitators from six countries completed online training (internal and external); Canada (n=1), Czech Republic (n=1), Netherlands (n=2), Republic of Ireland (n=1), United Kingdom (n=5). Training to date has been received well. In total 100% of participants found training to be beneficial. Preliminary feedback included "Canvas was good and easy to navigate"; "Training excellent and covered all aspects for the internal and external facilitator".

Conclusion: Supporting online education of nursing home staff is accessible and feasible to deliver at an international level. Preliminary data signals that even with social distancing restrictions, nursing home staff can still be supported to hold conversations with family carers virtually regarding resident's EoL needs.

Abstract number: A-17
Abstract type: Poster

Implementing ePROM in Specialist Palliative Home Care: Professionals' Perspective

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Background: Over the last decades, patient-reported outcome measures (PROM) have been developed for a better understanding of patient needs. The Integrated Palliative care Outcome Scale (IPOS) is an internationally recommended PROM-tool in Palliative Care. The validated electronic version of IPOS (eIPOS) is currently implemented in four German specialist palliative home care (SPHC) teams for use in everyday clinical practice. Patients report symptoms and concerns through eIPOS, which are transmitted directly to the electronic patient record of the supervising SPHC-team.

Aims: The aim of the study is to explore the attitudes regarding acceptance and use of eIPOS by SPHC staff in their daily care routine.

Methods: Mixed-methods sequential explanatory design with an anonymized online survey with all staff members of the four SHCP teams participating in the overall project (n=45-50). In the following qualitative approach ambiguous results from the descriptive analysis of the questionnaire will be discussed in two focus groups (n = 10-16). Data collection will be completed in April 2021.

Results: Quantitative and qualitative results will be combined to assess acceptance and use of eIPOS by SPHC staff in daily care routine. To our knowledge, this mixed-methods approach will be the first to examine providers' perspectives on the use of electronic PROMs in SPHC in this comprehensive manner.

Conclusion/Discussion: This study design allows broad information about professionals' acceptance of the eIPOS through the quantitative survey combined with a deeper understanding of SPHC staff perspectives from the focus group discussion. The results will be a central contribution to the objective of the overall project, which is piloting eIPOS in SPHC.

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Abstract number: A-18
Abstract type: Poster

Voices That Take Care – The Project Implementation

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Subtitle: Palliative Care Disclosure Podcast

Introduction: The elaboration of this project was born from the concern of a group of health professionals who, in their daily practice, felt that it still exists a lack of knowledge about what palliative care is: to whom it is intended to and where it intervenes. We thought that we could do better for the promotion and divulgation of palliative care in our area of intervention, concretely through the creation of a podcast seeking to give voice to those who care, regardless of being a health professional or a caregiver.

Objectives: To sensitize, promote and disclose palliative care.

Material and Methods: Creation of a podcast that gives voice to those who care. The "episodes" will be published on 01/03/2021, every two months. Each "episode" will have a duration of 5 minutes. It will be published on the website of the association and shared via social networks and via email to national long-term care network institutions and nursing homes.

Results: In September 2021, we will disclosure the data and will reveal the number of downloads and the feedback from the institutions to which the podcast was sent. Although it is difficult to evaluate the results by the number of downloads of each podcast, with these actions we aim to, above all, reach a greater number of people and health professionals. Active involvement in this philosophy of care contributes to greater literacy in palliative care, promoting humanization.

Conclusions: Sensibilization of both general population and health professionals, allows the person with illness and their family/caregiver to have greater support, to know the resources in the community and, above all, to become active members in the search for more and better assistance.

Abstract number: A-19
Abstract type: Poster

A Realist Synthesis of Mobile Application-enabled Communication for Patients in End-of-Life Care and in Light of the COVID-19 Pandemic

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Background: The COVID-19 pandemic restrictions have led to extended usage of virtual communication technology in healthcare, especially via mobile applications. Understanding the adoption of mobile application-enabled communication in end-of-life care in particular is important to improve its usage for patients and carers. This is a pertinent topic in light of the pandemic and the higher health risks of this population group.

Aims: To explore the use of mobile application-enabled communication for end-of-life care patients and their carers.

Methods (design, data collection, analysis): A realist synthesis approach is being adopted, using six databases and other information sources from 2005 to present. Data screening and quality assessment will be carried out by two reviewers independently. Discrepancies and disagreements will be discussed and resolved by a third reviewer. Data abstraction will use the context, mechanism, and outcome approach to capture specific information about the theories around the development, adoption, and use of mobile application-enabled technologies in end-of-life care. (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=231535)

Results: A total of 666 abstracts were screened and 218 full texts are being analysed. The project is ongoing, and the results will be presented at the meeting. A summary table of the theories around the development, adoption, and use of mobile application-enabled technologies in end-of-life care will be used to create a logic model of the link between empirical data and theories.

Conclusion / Discussion: The study will highlight the theories which explain the adoption of technology use in end-of-life care. The realist synthesis uses the available theories as a starting point and the empirical findings to build on these. The results will help to inform the applicability of a blended model of face-to-face and virtual communication after the end of the pandemic.

Abstract number: A-20
Abstract type: Poster

Decision Trees to Support Use of Palliative Care Guidelines in Daily Practice – Outcomes of Interviews and a Focus Group

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Background: Currently, Dutch palliative care guidelines are made available in a textual format. Within the oncology domain, there is experience translating guidelines into decision trees to create a human-readable, computer-interpretable version of the guidelines which can be used for decision support. Two palliative care guidelines have recently been translated into decision trees.

Aims: Our aim was to explore current use of palliative care guidelines by healthcare professionals; to identify use cases in which the decision trees format could provide additional benefits.

Methods: We conducted interviews and a focus group with healthcare professionals with palliative care experience, asking how they used palliative care guidelines in daily practice and probing the participants for feedback on the decision trees which have been created. From the interviews, we derived situations in which guidelines are used in daily practice. Subsequently, we asked the focus group participants to rate these situations on two criteria: importance and satisfaction with guidelines as a tool to help resolve the situation; and further discussed the top 3 which were of most interest to the group, exploring pains and expectations.

Results: 10 healthcare professionals participated (4 primary care, 4 hospital and hospice setting, 2 other setting; 6 of whom were palliative care specialist). They identified the following situations as being most important to them but not well satisfied by current guidelines and decision trees:

- Support decision making: clear overview of options and practical guidance.
- Provide patient-oriented information: clearly show patients what to expect.
- Work out relationships between symptoms which commonly occur together.

Conclusion: We identified situations important to healthcare professionals in which decision trees could support guideline use in daily practice. We will use this input to further improve and develop the decision trees.

Abstract number: A-21
Abstract type: Poster

Weekly Monitoring of Patient-reported Outcomes in Routine Medical Care: A Pilot Study

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Background: Systematic monitoring of patient-reported outcomes improves symptom management and overall quality of life. We piloted a novel nurse-led care model 'Supportive and Palliative Care Review Kit in Locations Everywhere' (SPARKLE) to monitor and address patient-reported concerns promptly.
Aim: This pilot study aims to identify common patient-reported concerns among Stage 4 lung cancer patients.
Methods: 25 patients with Stage 4 lung cancer were recruited from the National Cancer Centre of Singapore (NCCS) outpatient clinic.
For 12 weeks, participants completed a weekly online survey (Integrated Palliative Outcome Scale, IPOS) to self-report their symptoms or concerns. Identified problems from IPOS were followed up and managed by the nurse.
Results: Completion rate of the weekly IPOS declined over 12 weeks but was consistently above 50%. Weakness was the most common symptom to be reported (72%), followed by pain (65%), shortness of breath (59%), mobility (58%), drowsiness (55%), constipation (52%) and oral issue (51%). Other less commonly reported symptoms include itchiness (12%), headache (9%) and finger numbness (6%). Severity of reported weakness & pain were mainly mild (38% – 45%), while 30% - 35% conveyed severity of moderate to severe. It was shown that patients who rated their symptoms as mild were able to self-manage themselves adequately. Whereas prompt follow up was required for those rating moderate to severe symptoms.
This study highlights that patients are able to self-report their symptoms and severity. They were able to self-manage mild symptoms and required clinician assistance for more severe symptoms to provide timely directions to their care.

Abstract number: A-22
Abstract type: Poster

Evaluating the Online Response to a Guide to Support People who Are Caring for Dying Friends and Family, the 'Deathbed Etiquette: An Analysis of Twitter and Newspaper Comments

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Background: The guide to Deathbed Etiquette was created in 2019 by The Centre for the Art of Dying Well (@artofdyingwell) to support those at the bedside of a loved one who is dying. Updated guidance was developed in 2020 in response to the COVID-19 pandemic. During the COVID19 pandemic, many people (healthcare professionals and lay) have discussed the guide online; however, the nature of these discussions has not been examined.
Aims: To evaluate the online response to the Deathbed Etiquette guide.
Methods: We conducted a retrospective 2-year analysis of social media and newspaper comments, which referenced the Deathbed Etiquette guide. We conducted a sentiment analysis of three UK online newspaper comments about the guide. On Twitter, we analysed sentiment and frequency of tweets using the #deathbedetiquette hashtag; we also explored the relationship of this data with tweets from the @Artofdying Twitter account.
Results: 104 Tweets included the #deathbedetiquette hashtag (with 272 retweets and 432 likes). Three peaks in tweet intensity corresponded with promotional activity from the @Artofdyingwell account. These dates were July 2019 (Deathbed etiquette launch), August 2019 (attention from Catholic Church and media) and April 2020 (relaunch of COVID19 guide). Sentiment on Twitter was positive with no negative tweets. The newspaper sentiment analysis demonstrated how the public voiced both supportive, but more negative comments about the guide. For example, some people did not like the term etiquette or the directive structure of the guide. They also disliked what they considered to be the depressing subject matter.
Conclusion: Online discussion about the Deathbed Etiquette was varied. Our data demonstrates the potential to use social media and online comments to gain understanding about palliative care interventions. Future work can examine the content of these discussions in greater depth and include other social networks, newspapers and digital formats.

Abstract number: A-23
Abstract type: Poster

Internet Accessibility and Willingness of Patients with Chronic Respiratory Disease to Use an Internet-based Breathlessness Self-management Intervention

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Introduction: Breathlessness support services for patients with chronic breathlessness improve patients' self-management and reduce their distress due to breathlessness. The provision and access to such services within the UK's National Health Service is limited. Delivering online breathlessness supportive services maybe one way of improving access to non-pharmacological self-management interventions for people living with chronic breathlessness.
Aim: To explore internet accessibility and willingness of patients with chronic respiratory disease to use an internet-based breathlessness self-management intervention.
Methods: Patients attending 3-specialist respiratory outpatient services at a large NHS Foundation Trust over a 2-week period (prior to the COVID-19 pandemic) completed a standardised questionnaire regarding internet accessibility. The questionnaire asked; if the patient had internet access, modes of accessing the internet, frequency of internet use and if they would use an internet based breathlessness support service.
Results: 46 patients (COPD: 19, Bronchiectasis: 22, Asthma: 4), 17 male, with a median (range) age 68 (41 – 86) years, MRC Dyspnoea Score of 2 (2-4) completed the questionnaire. Of these, 35 (76%) patients had access to the internet at home; 28 (61%) accessed the internet daily; and 26 (57%) had two or more modes of accessing the internet. Of the 35 patients with home internet access, 33 (94%) reported that they would use an internet-based breathlessness self-management intervention, if available.
Conclusion: These preliminary findings suggest that patients that have access to the internet would use an internet-based breathlessness self-management intervention, if given the opportunity.

Abstract number: A-24
Abstract type: Poster

Democratising Death Using Technology during the COVID-19 Pandemic

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Background: MyWishes is a free to use, end of life planning software for people who live in the United Kingdom. It uses 'social media design' principles and takes a non-medicalised approach to care planning. The innovation was developed following years of research and develop and piloted with a number of hospices before before it was launched.
Aims: To help people make plans for themselves and their loved ones. When the COVID-19 pandemic started we decided to make everything on MyWishes free to use and in doing so, democratise end of life planning. The platform is suitable and accessible to both hard to reach demographics and society at large.
Methods (design, data collection, analysis): We wanted to reinvent care planning and make it relevant for today's digitally savvy generation. It was important that despite providing a complex and data entry and heavy platform the service was intuitive and simple to use. This was achieved by providing a consistent design interface, adopting a complimentary colour scheme and providing video tutorials in each section.
Obtaining feedback from inpatients at Michael Sobell Hospice and St Francis Hospice have helped improve our understanding of how MyWishes is used within clinical settings. Ongoing work with patient and user groups remains vital to our ongoing development.
Results: MyWishes has been featured in a number of public facing publications. These range from the Times and the Metro newspapers to PC Pro and BJ Miller's most recent publication 'A beginner's guide to the end'. Our community is growing and we continue to advocate for the normalisation of care planning through the use of technological innovation.
Conclusion / Discussion: Technology will continue to play an important part in care planning. It is important to discuss whether 'digital first' interventions are suitable for some populations and how technology can be used without eroding quality of care and compassion.

B Posters Pain and Symptom Management

Abstract number: B-02
Abstract type: Poster

Recommendations for Deprescribing Medication in the Last Phase of Life: An International Consensus

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Background: Several tools for deprescribing medication have been published. However, most have been developed for specific patient groups and do not define the clinical situation or other prompts for which deprescribing may be considered.
Aims: To find consensus on recommendations about deprescribing medications for adult patients with a life expectancy ⩽6 months.
Methods: Experts in the field of palliative care were invited to participate in an international Delphi study. Existing tools were integrated in a list of 42 recommendations regarding the deprescription of specific types of medication. Experts were asked to rate their agreement with each recommendation on a Likert-scale from 1 to 5 (strongly agree – strongly disagree), starting for patients with a life expectancy ⩽6 months and, in case of no agreement, asked for patients with shorter life expectancies. Consensus was reached in case ⩾70% of experts agreed with a recommendation, the IQR was ⩽1 and ⩽10% strongly disagreed.
Results: 47 experts from 11 countries participated (response rate 53%). For patients with a life expectancy ⩽6 months, consensus was reached for 32 (86%) recommendations. 11 considered the deprescription of cardiovascular medication given for mild-moderate hypertension and/or the prevention of cardiovascular events. Experts also agreed on 11 recommendations which considered deprescribing antiplatelet therapy, anticoagulants and blood glucose lowering drugs in case of complications or if prescribed for prevention of future events. For the 5 recommendations without consensus for a life expectancy ⩽6 months, consensus was reached for 1 recommendation in case of a life expectancy ⩽1 month, namely deprescription of proton pump inhibitors prescribed for uncomplicated gastric/oesophageal disease.
Conclusion: A high level of consensus was reached on recommendations for deprescribing medications in patients with a life expectancy of ⩽6 months.
This study is part of iLIVE, a EU funded research

Abstract number: B-03
Abstract type: Poster

Visualizing how to Use Parenteral Opioids for Terminal Cancer Dyspnea: A Pilot, Multicenter, Prospective, Observational Study

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Background: How physicians use opioids for dyspnea in imminently dying cancer patients (terminal dyspnea) varies markedly, which could hamper quality care.
Aims: To examine the adherence to an algorithm-based treatment for terminal dyspnea, and explore its efficacy and safety over 24 hours.
Methods: This was a pre-planned subgroup analysis of a multicenter prospective observational study. Inclusion criteria were: advanced cancer patients admitted to palliative care units, ECOG PS=3-4, and a dyspnea intensity⩾2 on the Integrated Palliative care Outcome Scale (IPOS). We developed an algorithm to visualize how palliative care physicians would use parenteral opioids. Participating physicians initiated parenteral opioids, choosing whether to use the algorithm based on their preference. We measured the adherence rate to the algorithm over 24 hours

(predefined goal=70%), and compared dyspnea IPOS scores and adverse events between patients with and without algorithm-based treatment.
Results: Among 1896 patients included in the main study, 164 received parenteral opioids for terminal dyspnea with (n=71) or without (n=93) the algorithm. No significant between-group difference was noted in the baseline characteristics. Of 164 patients (median survival=5 days), 22 developed cognitive impairment, 15 died, and 1 discontinued opioid within 24 hours. 70 of 71 patients (99%; 95%CI=92-100%) adhered to the algorithm over 24 hours. In a complete case analysis, mean dyspnea IPOS scores significantly decreased from 2.9 (SE=0.1) to 1.5 (0.1) in the algorithm group (n=54; $p<0.001$), and 2.9 (0.1) to 1.6 (0.1) in the non-algorithm group (n=72; $p<0.001$). There was no significant between-group difference in changes in dyspnea IPOS scores (p=0.65). Adverse events were rare (n=5).
Conclusion: The algorithm-based treatment was easy to follow, and as effective and safe as the specialist-level treatment. Its implementation may help non-specialist physicians provide quality care for terminal dyspnea.

Abstract number: B-09
Abstract type: Poster

Effectiveness of Naldemedine and Magnesium Oxide in Preventing Opioid-induced Constipation: Proof-of-Concept, Two-arm, Open-label, Phase II Randomized Controlled Trial (MAGNET Study)

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Background: Opioid-induced constipation (OIC) may occur in patients receiving opioid treatment and decrease their quality of life (QOL).
Aim: We compared the effectiveness of magnesium oxide (MgO) and naldemedine (NAL) in preventing OIC.
Methods: This proof-of-concept, randomized controlled study included 120 patients with cancer scheduled to receive opioid therapy. They were randomly assigned (1:1) using a computer-based system and stratified by age and sex to receive MgO (500 mg, thrice daily; MgO group) or NAL (0.2 mg, once daily; NAL group) for 12 weeks. Change in the Japanese version of Patient Assessment of Constipation QOL (JPAC-QOL) from baseline to 2 weeks was assessed as the primary endpoint. Change in the JPAC-QOL from baseline to 12 weeks, spontaneous bowel movements (SBM) , the complete SBM (CSBM) from baseline to 2 and 12 weeks was assessed as exploratory endpoints. Efficacy analysis was performed considering intention-to-treat. This trial was registered in the University Hospital Medical Information Network (UMIN) Clinical Trials Registry (UMIN000031891).
Results: Between March 26, 2018 and June 30, 2019, 166 patients were screened for inclusion and 60 patients were randomly assigned to the MgO or NAL group. Change in JPAC-QOL was significantly lower in the NAL group than in the MgO group after 2 weeks (MgO vs NAL; 0.5 vs -0.01, $P < 0.001$) and 12 weeks (0.4 vs 0.03, $P < 0.001$). There was no significant difference in the change in SBMs between the groups at 2 and 12 weeks. The CSBM rate was higher in the NAL group than in the MgO group at 2 weeks ($P = 0.02$) and 12 weeks ($P = 0.01$). There were fewer adverse events in the NAL group than in the MgO group. No serious adverse events or death occurred.
Conclusion: In patients with cancer experiencing OIC, naldemedine significantly prevented deterioration in defecation QOL and CSBM rate compared to magnesium oxide.

Abstract number: B-11
Abstract type: Poster

Efficacy of Proportional Sedation and Deep Sedation Defined by Sedation Protocols: A Multicenter, Prospective, Observational Study

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Background: There are inconsistencies in empirical studies about what is continuous deep sedation in clinical practice.
Purpose: To investigate the efficacy of two types of palliative sedation: proportional and deep sedation, defined by sedation protocols.
Methods: We conducted a multicenter prospective observational study of consecutive cancer patients who received the continuous infusion of midazolam for refractory symptoms based on protocols in 14 palliative care units. The primary endpoint was goal achievement at 4 hours: in proportional sedation, symptom relief (Integrated Palliative care Outcome Scale: IPOS$\leqslant$ 1) and absence of agitation (modified Richmond Agitation-Sedation Scale: RASS$\leqslant$ 0); in deep sedation, the achievement of deep sedation (RASS$\leqslant$ -4). Secondary endpoints included deep sedation as a result, communication capacity (Communication Capacity Scale item 4$\leqslant$ 2), IPOS and RASS scores, and adverse events.
Results: Among the 1633 patients, 154 received the continuous infusion of midazolam. Responsible palliative care specialists decided to use the protocols for 81 patients: proportional sedation (n=64), and deep sedation (n=17). The goal was achieved in 77% (n=49; 95% confidence interval, 66-87) with proportional sedation; and 88% (n=15; 71-100) with deep sedation. Deep sedation was necessary for 45% of those who received proportional sedation. Communication capacity was maintained in 34% with proportional sedation and 10% with deep sedation, respectively. IPOS decreased from 3.5 to 0.9 with proportional sedation, and 3.5 to 0.4 with deep sedation; RASS decreased from $+0.3$ to -2.6, and $+0.4$ to -4.2, respectively. Fatal events related to the treatment occurred in 2% (n=1) with proportional and none with deep sedation.
Conclusion: The two types of sedation protocol were effective to achieve each treatment goal.

Abstract number: B-12
Abstract type: Poster

Delirium Management within an Inpatient Palliative Care Unit: Introduction of the Modified TIME Bundle

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Background: Delirium affects up to 88% of patients with palliative care needs and can be an extremely distressing experience. Therefore, prompt recognition and correct management can improve the end-of-life experience for both patients and families.
Aim: Based on the recent Scottish Intercollegiate Guidelines Network (SIGN) Guideline for Risk Reduction and Management of Delirium, the primary aim of this project was to improve the management of delirium, with 75% of patients having appropriate investigations and management documented in their medical notes. Secondary aims were for all patients with a delirium diagnosis to have the term "delirium" recorded in their medical notes by both medical and nursing staff, and to improve staff knowledge and confidence.

Methods: In a Specialist Palliative Care Inpatient Unit in Scotland, three cycles of a PDSA (Plan-Do-Study-Act) model were carried out. The interventions of these cycles were: Education on Delirium & the 4AT; Education on the Modified TIME (Triggers, Investigate, Management, Engage & Explore) Bundle; Implementation of the Modified TIME Bundle. Data for each cycle was collected over two weeks. A questionnaire containing both knowledge and confidence-based questions was performed at the start and end of the project.

Results: Results of each cycle can be seen in the table below. A maximum of 27 patients were present in the hospice over each period, with 11-25% diagnosed with delirium.

	Baseline (n=3)	*Cycle 1* Education - Delirium & 4AT (n=5)	*Cycle 2* Education - TIME Bundle (n=6)	*Cycle 3* TIME Bundle Inroduction (n=4)
Use of 4AT to screen for delirium	33%	60%	67%	75%
Cause of delirium treated	67%	60%	67%	100%
Non-pharmacological management utilised	33%	20%	100%	100%
Pharmacological management utilised	67%	40%	83%	75%
Delirium recorded by medical & nursing staff	0%	20%	33%	0%
Delirium recorded by medical staff only	67%	20%	50%	75%
Staff confidence in recognising delirium	66% (Quite/ Very confident)	–	–	71% (Quite/ Very confident)

Discussion: This is a significant issue affecting patients with palliative care needs and although only small sample sizes were involved, improvements could be seen in most aspects after simple interventions. The 4AT was utilised in more patients to assess for delirium. More patients received appropriate management, both pharmacological and non-pharmacological. Improvements can still be made and so ongoing staff education is taking place and further evaluations will be done.

Abstract number: B-13
Abstract type: Poster

Sedation at the End of Life in Hospital: A Multicenter Retrospective Cohort Study

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Background: Data on sedation at the end of life (eol) based on objective criteria, rather than professionals' self-reports, are scarce, as well as data across disciplines.

Aims: To assess the use of sedatives with "continuous effect" within the last week of life and associated factors in different hospital departments, based on objective criteria.

Methods: Multicenter retrospective cohort study, using medical records of patients who died in 5 German hospital departments 01/2015–12/2017 (hemat-/oncology (n=2), neurology, geriatrics, gynecology). Analysis of sedatives recommended in guidelines for "palliative sedation": benzodiazepines, levomepromazine, haloperidol ($\geqslant$ 5 mg/day) and propofol. Published definitions of "continuous effect" and "at least moderately sedating" doses were used. Descriptive statistics and multivariate logistic regression analysis (R version 3.6.1).

Results: 260/517 (50%) deceased patients received a sedative with "continuous effect" during the last week of life, 53/517 (10%) in "at least moderately sedating" doses. For 76/260 (29%) patients, no indication was noted. The term "sedation" was documented for 20/260 (8%) patients, involvement in decision making for 4/260 (2%). Prevalence of use of sedatives with "continuous effect" differed significantly between departments. Use of sedatives with "continuous effect" was significantly associated with age (OR 0.98, 95%-CI 0.96 to 1.00), support by a specialist palliative care team (OR 5.59, CI 3.65 to 8.69), documentation of the term "palliative treatment" (OR 2.25, CI 1.39 to 3.70), and department (hemat-/oncology II: OR 0.32, CI 0.16 to 0.63; geriatrics: OR 0.23, CI 0.10 to 0.50; reference: hemat-/oncology I).

Conclusion: The observed differences between departments and deviations from recommended practice warrant further exploration and development of context-specific support measures for sedation at the eol.

Funding: Bundesministerium für Bildung und Forschung (01GY1712, SedEol)

Abstract number: B-15
Abstract type: Poster

Perceptions on the Use of Opioids in COVID-19: Survey among Members of the German Association for Palliative Medicine (DGP)

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Background: Opioids efficiently alleviate pain and dyspnea. However, guidelines on symptom management with opioids differ which may lead to an uncertainty concerning opioid indication and ethical implication among medical staff, especially when caring for COVID-19 patients.

Aims: We aimed to examine the perception of members of the German Association for Palliative Medicine (DGP) concerning the administration of morphine as the gold standard opioid for symptom control *within and outside of a palliative care (PC) setting*, including care for COVID-19 patients.

Methods: DGP members received an anonymized online questionnaire (Survey Monkey®), containing questions regarding their perception of symptom management with morphine in general, and in particular concerning COVID-19 patients. Participants were asked to rate their perception *within and outside* of a PC setting.

Results: N=506 of 6129 DGP members participated. DGP physicians and nurses perceived handling of morphine as "certain and confident"(98%) and "clearly regulated" *within PC* (95%), but rated these items

significantly lower for *outside PC* (48%/38%). When caring for COVID-19 patients, handling of morphine was even less often rated “certain and confident”(26%) or “clearly regulated” (23%) for *outside* PC. Dyspnea (99%/52%), relief of the dying process (62%/37%), restlessness (30%/15%) and fear/panic (27%/13%) were more frequently rated as general indications for morphine *within* versus *outside PC*. Most participants (89%) wished to involve palliative care consultation teams.
Conclusions: DGP members perceived substantial uncertainty in the handling of morphine for medical fields *outside* PC. Uniform interdisciplinary guidelines for symptom control, more education and involvement of a PC consultation team should be increasingly considered in the future.

Abstract number: B-16
Abstract type: Poster

Symptom Burden in Patients in SAPV and AAPV over Time - Data from the APVEL Study

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Background: Data from the Integrated Palliative Care Outcome Score (IPOS) of n = 215 patients from the prospective survey of the APVEL project are reported. The project was carried out in North Rhine-Westphalia, a region with established structures of both general outpatient palliative care (AAPV) and specialized outpatient palliative care (SAPV).
Aim: The focus of this sub-project was to describe the principles of effectiveness of SAPV compared to AAPV in urban and more rural regions. The APVEL project is one of three supported innovation fund projects with the aim of making recommendations on the national SAPV guideline of the Federal Joint Committee (G-BA).
Methods: The IPOS is a validated 5-point Likert instrument that contains 10 questions about physical symptoms, but also covers psycho-social areas. The IPOS was supplemented by two single-item questions on the impact dimensions “security promise” and “everyday framing” based on the work of Schneider et al (2015). At approximately five-day intervals after the initial on-site survey, up to three follow-up surveys were carried out by telephone. A multivariate ANOVA was carried out using STATISTICA © software and Microsoft Excel 2017 © to analyze the data.
Results: SAPV patients showed a higher total IPOS total score and the physical symptoms, as well as the symptom “weakness”, constant over time, while the AAPV values continuously decrease over time. The “feeling of security” experienced in the SAPV and AAPV was consistently good over time, but always better in the city compared to the country. According to the trend, a comparable picture emerged for the construct “normality” in framing everyday life.
Conclusions: The results suggest that patients in the SAPV showed a higher symptom burden and poor functionality. Nevertheless, it was possible to bring about a stabilization over the course of time and to ensure that patients may remain at home.

Abstract number: B-17
Abstract type: Poster

Development of Criteria for Identifying Potentially Inappropriate Prescribing of Medications for Symptomatic Relief in Older Adults with Cancer Receiving Palliative Care (PIP-CPC)

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Background: Targeted action is needed to improve prescribing in older adults with cancer at end-of-life. Existing prescribing tools for patients with advanced cancer focus on identifying medications for pre-existing conditions (e.g. statins) that may be suitable for deprescribing. However, these tools do not assess medications for controlling symptoms commonly experienced towards end of life (e.g. pain).
Aims: To develop criteria for identifying potentially inappropriate prescribing of medications for symptomatic relief in older adults (⩾65 years) with cancer who are receiving palliative care and have an estimated life expectancy of <1 year.
Methods: A two-round electronic Delphi consensus exercise was conducted with a panel of 18 stakeholders with expertise in palliative care, oncology and/or geriatric medicine across Ireland and the United Kingdom. Panellists rated their agreement with a series of criteria using a Likert scale and had the option of adding free-text comments. A priori decision rules were used to accept or reject criteria.
Results: Following Round 1, group consensus was achieved for 15/28 criteria which were included in the final set of criteria. Four criteria were removed based on the panel’s ratings and additional comments. Group consensus was achieved for all nine criteria included in Round 2. The final set comprised 24 criteria relating to: anorexia-cachexia (n=1); anxiety (n=2); constipation (n=5); delirium (n=1); depression (n=3); diarrhoea (n=1); dyspnoea/breathlessness (n=1); fatigue (n=2); insomnia (n=2); nausea/vomiting (n=2); pain (n=3); duplicate drug classes (n=1).
Conclusion/discussion: Prescribing criteria have been developed for identifying potentially inappropriate prescribing of medications for symptomatic relief in older adults with cancer receiving palliative care. Future studies should examine the application and validity of these criteria.
Funding: Irish Cancer Society, All Ireland Institute of Hospice and Palliative Care.

Abstract number: B-18
Abstract type: Poster

Episodic Dyspnea in Advanced Lung Cancer Patients: Prevalence, Clinical Features and Risk Factors. A Nation-wide, Multi-center, Descriptive, Cross-sectional Study

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Background: Reported ED frequency in cancer is variable depending on ED definition used and population characteristics. No studies in advanced lung cancer (LC) patients (Pts) have been conducted.
Aims: To determine the prevalence of ED in advanced LC out-Pts. To describe ED clinical characteristics & identify risk factors.
Methods: Consecutive advanced LC Pts visited in Palliative Care or Oncology clinics of 10 Spanish hospitals. A sample of 351 Pts are needed to estimate ED frequency. Inclusion criteria:⩾18 y-old, stage III-IV LC &

signed informed consent. Exclusion criteria: cognitive impairment, difficulty to understand & comorbidity acute exacerbation. Logistic & multinominal regressions were done to assess ED risk factors.

Results: 366 Pts included. Background dyspnea (BD) in 35.5% Pts. ED in 31.9% (90% in Pts reporting BD). Men:67.5%. Mean age: 65 y-old. ECOG≤1:59.4%. Pts on disease-oriented therapy:72.9%. Median ED episode/day:1 (IQR: 1-2); median intensity:VNS 7/10 (IQR: 5-8.25). Triggers reported by 89.9% Pts (exercise:96.2%; emotions:40%). ED Pts had an oxygen therapy OR=9.89. See in Table 1 differences in comorbidities between Pts with & without ED.

Variable	**CC**	**All sample**	**Patients not reporting ED (n (%))**	**Patients reporting ED (n (%))**	**P-value**
		366 (100)	249 (68.1)	117 (31.9)	
COPD history	366	110 (30.1)	64 (25.7)	46 (39.3)	0.011
Vascular pulmonary disease (VPD) history	366	16 (4.4)	5 (2.0)	11 (9.4)	**0.003**
Heart failure (HF) history	366	21 (5.7)	9 (3.6)	12 (10.2)	**0.021**
Cachexia	366	41 (11.2)	18 (7.3)	23 (19.7)	**0.002**
Disease-oriented therapy	365	266 (72.9)	195 (78.3)	71 (61.2)	**<0.001**
Supportive care only		84 (23.0)	42 (16.9)	42 (36.2)	**<0.001**
No treatment		15 (4.1)	12 (4.8)	3 (2.6)	0.404

CC: complete cases; COPD: Chronic Obstructive Pulmonary Disease

Conclusion: ED prevalence in advanced LC Pts is high (90%) in those with BD. Pts with intrathoracic comorbidities (COPD, VPD, HF), cachexia or on supportive care reported ED more frequently. ED Pts have ≈10-fold risk of needing oxygen therapy, indicating alveolar oxygen-exchange failure.

Abstract number: B-19
Abstract type: Poster

A Systematic Review of Quality Improvement Initiatives for Continuous Sedation until Death

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Background: Extensive debate surrounds the practice of continuous sedation until death within end-of-life care.

Aim: To provide insight into existing initiatives to support the practice of continuous sedation until death and assess their feasibility and effectiveness.

Methods: Systematic review and narrative synthesis, registered on PROSPERO (CRD42020149630). Records were searched through MEDLINE, EMBASE, CENTRAL, CINAHL and Web of Science from inception to April 16 2020. Peer-reviewed studies reporting original data on initiatives to support the practice of continuous sedation were included for review.

Results: Twenty-one studies met the criteria and were included. Initiatives were focused on assessment tools of consciousness and discomfort (9), the use of guidelines and protocols (8) and expert consultation (3). All initiatives were reported as useful, acceptable and feasible. Studies on the use of monitoring devices showed that a small proportion of patients were found to be awake, despite the patient being unresponsive according to the observer-based sedation scales. However, the wide range of values of these monitoring devices for comfortable and adequately sedated patients seems to hamper its overall implementation in daily clinical practice. Physicians reported changes in practice conform to guideline recommendations but the shift was modest at best. Expert consultation was regarded as supportive when sufficient expertise is lacking and helpful in avoiding possibly unnecessary sedations.

Conclusions: The reviewed initiatives may contribute to improvement of continuous sedation until death, though their evidence base is rather limited. More insight is needed into their feasibility, preconditions for effective implementation and impact in actual practice.

Abstract number: B-23
Abstract type: Poster

Are Non-pharmacological Strategies Sustained 6 Months after Patients with Chronic Obstructive Pulmonary Disease (COPD) Attend a Breathlessness Service? A Qualitative Study

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Background: The Westmead Breathlessness Service (WBS) trains patients with moderate to very severe chronic obstructive pulmonary disease (COPD) to self-manage chronic breathlessness over an 8-week program with multidisciplinary input and home visits.

Aims: This study aimed to explore the degree to which non-pharmacological strategies were sustained 6 months after completing the WBS program.

Methods: A qualitative approach was taken, using semi-structured telephone interviews. Thematic analysis used an integrative approach.

Results: Thirty-two participants were interviewed. One or more breathlessness self-management strategies were sustained by most participants, including breathing techniques (n=22; 69%), the hand-held fan (n=17; 53%), planning/pacing and exercise (n=14 for each; 44%), and strategic use of a 4-wheeled walker (n=8; 25%). However, almost a third of participants appeared to be struggling psychologically, and a ‘chaos narrative’ appeared to be prevalent. Transcripts suggested that some participants had poor recall of the program.

Conclusions: Self-management strategies taught by breathlessness services to patients with moderate to very severe COPD have potential to be sustained 6 months later. However, psychological coping may be more challenging to sustain. Research is needed on ways to improve uptake of psychological interventions and the implications of poor recall on self-management.

Abstract number: B-24
Abstract type: Poster

An Audit and Review of the Efficacy of Sodium Valproate for Neuropathic Pain by a UK Hospital Palliative Care Team

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Background: The antiepileptic sodium valproate (valproate) can be used as an adjuvant in neuropathic pain management, as supported by clinical experience. However, there is lack of robust evidence on the efficacy of valproate in relieving neuropathic pain and the mechanism of action of valproate in neuropathic pain is unclear. Therefore, it is important to investigate the prescribing practice of valproate in neuropathic pain management and its efficacy.
Aims: First, to assess a UK hospital palliative care team's (HPCT) prescribing compliance of valproate against robust loco-regional guidelines in neuropathic pain management. Second, to begin exploration of valproate's efficacy and safety in palliative care patients.
Methods: 1941 referrals to the HPCT in 2019 were screened and prescriptions of 56 adults who had valproate started for neuropathic pain were compared against the guidelines. The historical inpatient records of these patients were studied comprehensively to investigate the efficacy and safety of valproate.
Results: The HPCT is 69.64% compliant with the guidelines (although when taking into account the need for subcutaneous dosing or renal failure this increases to 91%). The mode starting and maintenance doses prescribed were 400mg/day. Retrospectively, from the records, 18 patients reported positive outcome with valproate whilst 4 reported lack of response. 4 patients with a pain score recorded reported reduction in pain score after treatment, but only 1 had more than 50% reduction. 15 patients had other analgesic doses reduced following treatment with valproate, suggesting valproate may be an opioid-sparing agent. Adverse reactions were identified in 4 patients.
Conclusions: The HPCT has reasonable prescribing compliance. The positive results obtained on the efficacy and safety of valproate in neuropathic pain management in addition to its potential opioid-sparing effect should call for further exploration including RCTs against other agents.

Abstract number: B-25
Abstract type: Poster

Assessment and Management of Fatigue in Patients with Cancer: A Multi-centre Regional Audit

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Background: Fatigue is a common and debilitating symptom experienced by patients with life limiting illness.
Aim: To audit clinical practice against regional standards and to use outcomes to update regional standards and guidelines.
Method: A systematic literature review of the management of fatigue in cancer patients was performed. The practice of Healthcare Professionals working in specialist palliative care was surveyed and a multi-centre retrospective case note audit was performed.
Results: There is evidence for corticosteroid use and for educational and exercise interventions in the management of fatigue. There is limited evidence for the use of acupressure, acupuncture or psychostimulants.
58 clinicians participated in the survey. 9% report using an assessment tool to evaluate fatigue. 94% consider reversible causes. 54% reported their service area provided educational sessions covering fatigue. 52% refer patients for exercise based interventions or psychological support. Of those with access, 33% consider referral for acupuncture/acupressure. 80% use corticosteroids in fatigue management, with 93% using Dexamethasone 4mg. 17% consider use of psychostimulants.
116 case notes were reviewed. 32% of patients were screened using an assessment tool. A reversible cause was considered in 79%. 25% were referred for educational intervention, 18% for exercise intervention and 38% for psychological support. 37% of patients were commenced on a corticosteroid, with 51% prescribed Dexamethasone 4mg. No patients were referred for acupuncture/acupressure or commenced on psychostimulants.
Conclusion: The majority surveyed did not use an assessment tool. Most clinicians considered corticosteroids. However, around half did not consider referral for educational or exercise interventions. Psychostimulants were not prescribed. Respondents would consider referral for acupuncture/acupressure but this was not widely available.

Abstract number: B-26
Abstract type: Poster

Managing Medicines at Home for Terminally Ill Patients within Complex Systems of Care

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Background: Treatment advances enable patients to remain cared for and, increasingly, to die at home. As a result, families assume increasing responsibility for administering complex medication regimens and negotiating care with many different health care services and professionals.
Aim: To explore how terminally ill patients and their family caregivers undertake the work of medicines management within a complex system of care.
Method: Qualitative UK study including 1. semi-structured interviews with family care givers (21) and healthcare professionals (40) and 2. Longitudinal patient centred case studies (20). Thematic and narrative case analysis.
Results: Participants reported difficulties in navigating a system they experienced as complex and fragmented, particularly as the patient's illness progressed. 'Feeling known' within the system was not achievable without continuity of care. Family caregivers often came to assume the role of care coordinator and developed personally effective systems for managing medicines and recording use. Participants described the need to remain vigilant about the medicines prescribed for the patient and changes to prescriptions which could be hazardous. Delays in accessing services, and problems of communication between and with professionals were frequently encountered. Medicines management involved considerable effort, resourcefulness, and responsibility. Inability to rapidly access help in a crisis was intensely stressful.
Conclusion/discussion: The findings highlight the extent to which access to resources and personal agency is underpinned and enabled by interpersonal relationships within and between personal and professional networks. The availability of a key health professional to help navigate a complex and confusing system was important to a good experience of care.

Abstract number: B-27
Abstract type: Poster

Use of Ambulatory PCA for Children and Young People with Advanced Cancer: Evaluation of Use and Outcome

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Background: Pain is a leading symptom in children and young people (CYP) with advanced cancer. A multi-modal pain management approach is fundamental in paediatric palliative care. Despite this, pain is only effectively managed in 30% of CYP with advanced cancer. Use of ambulatory patient-controlled analgesia (PCA) for CYP at home is increasingly described as a safe and effective tool for managing pain in CYP towards the end of life (EOL).

Aim: Evaluate use and outcome of ambulatory PCA using a CADD Solis 2100 infusion pump for CYP with advanced cancer cared for at home.

Method: Nineteen month retrospective chart review (July 2019 - February 2021) of CYP with advanced cancer receiving specialist palliative care at home.

Results: Ten CYP, 8 males and 2 females aged from 3 to 16 years, were started on PCA during EOL care at home. One child was excluded as they returned to inpatient care. 9 children managed in the community were evaluated, all experiencing pain due to advanced cancer. Median duration of use was 6 days (3 to 140 days). All CYP continued on ambulatory PCA until EOL.

Mean number of PCA bolus doses given was 275 bolus/CYP or 13 boluses/day per CYP. In all 9 cases bolus delivery was facilitated by parent/carer proxy.

Most common medications delivered by PCA were: morphine and ketamine (4 cases), oxycodone and ketamine (3 cases), and methadone (2 cases). 1 patient required opioid rotation from PCA initiation to EOL; another CYP required midazolam added to the PCA for severe dyspnoea.

On average each patient needed 6 dose adjustments for effective analgesia. Median intravenous morphine equivalent dose at EOL was 0.96mg/kg/day (range 0.38 to 42.24mg/kg/day). No adverse events noted. One CYP experienced remote dose cord failure but was still able to receive PCA bolus via pump back up button.

Conclusion: Study provides further evidence that ambulatory PCA using CADD pumps can be used successfully and effectively in pain management of CYP with advanced cancer at home.

Abstract number: B-28
Abstract type: Poster

The Complex Management of Retroperitoneal Bleeding in a Palliative Patient on Therapeutic Anticoagulation

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Background: Spontaneous retroperitoneal bleeds are rare and thus there is limited information on their clinical features and management. They are thought to be one of the most serious complications associated with anticoagulation with a potentially high mortality of 30%. This is thought to be due to delayed recognition and inappropriate management. Thus this topic is particularly relevant in palliative medicine. However, retroperitoneal bleeding in a palliative patient has not previously been explored in the literature.

Aim: To highlight how retroperitoneal bleeding presents and evolve. To demonstrate how effective management requires input from multiple specialities including haematology, anaesthetics, interventional radiology and surgeons.

Method: Case of a 71 year old male with metastatic non-small cell lung cancer who was on low molecular weight heparin for a pulmonary embolus. This man presented with an acute inability to weight bear due to severe pain predominantly in his right buttock, hip and groin. Computed tomography venogram was requested due to an acute escalation in pain associated with an acute drop in haemoglobin and acute kidney injury. This revealed a new right psoas muscle haematoma. His anticoagulation was stopped, however his haemoglobin continued to drop despite blood transfusion and his clotting became deranged. Haematology was consulted and his coagulation normalised with tranexamic acid and vitamin K. He subsequently stabilised and he was able to mobilise without pain and his anticoagulation was reintroduced.

Results: Effective management required prompt recognition and consultation with haematology, anaesthetics, interventional radiology and surgeons. On stabilising anticoagulation was reintroduced according to haematology advice.

Conclusion: This case highlights that early recognition and multispecialty input is paramount in the management of retroperitoneal bleeding in a palliative patient on therapeutic anticoagulation.

Abstract number: B-29
Abstract type: Poster

A systematic environmental scan of online self-management resources for adults living with primary brain cancer and their carers

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Introduction: Primary brain cancer has a profound effect on the lives of a person who is diagnosed, and their families/carers. Seeking information on a newly diagnosed disease is frequently prioritised to inform care planning and self-management of disease, often from internet resources.

Aim: To appraise the content, reliability, and readability of the available online self-management resources for adults living with primary brain cancer, and their families/carers.

Method: A systematic environmental scan of online resources designed for adults (>25 years) living with primary brain cancer, published in English from 2009-19, was undertaken. Resources were classified by:

1) the step on the cancer care continuum;
2) self-management domains (PRISMS taxonomy);
3) basic information disclosure (Silberg criteria);
4) independent quality verification (HonCode);
5) reliability of disease and treatment information (DISCERN); and readability (Flesch-Kincaid reading grade).

Results: A total of 119 online resources were identified, most originating in England (n=49); Australia (n=27); or the USA (n=27). Resources for active treatment (n=76) were the most common, versus palliative care (n=13), recurrence (n=3) or survivorship (n=1) resources. Few resources directly provided self-management advice. Resources rarely cited verifiable evidence (n=26, 22%), or were HonCode certified (n=9, 24%). The median resource reliability (DISCERN) was 56%. A median of 8.8 years of education was required to understand these online resources.

Conclusion: Online resources for brain cancer lack specific, practical and accessible self-management advice to address patient and carer needs across the cancer care continuum. Resources targeting rehabilitation, managing behavioural changes, survivorship, recurrence, and palliative care must be prioritised for development. Developing resources that are accessible for people with poor literacy or cognitive deficits is also critical for this patient cohort.

Abstract number: B-30
Abstract type: Poster

"You Don't Want to Sedate Him". A Qualitative Interview Study on the Intentions of Administering Sedative Drugs at the End of Life in Nursing Homes and Hospital Departments

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Background: Previous data indicate major differences between countries and settings regarding the intention of administering sedative drugs, and which drugs are perceived to be sedating.

Aims: To explore the concept of 'sedative drugs' and the intentions of German healthcare professionals in general palliative care when administering sedative drugs at the end of life.

Methods: We conducted 49 semi-structured qualitative interviews with physicians and nurses in five hospital departments (haematology/oncology (n=2), neurology, geriatrics, gynaecology) and four nursing homes. Recruitment took place via contact persons in each participating centre. We thematically analysed the transcripts by the Framework approach, using MAXQDA version 2018.2.

Results: Most interviewees referred to benzodiazepines, opioids, and antipsychotics. Some subsumed all into the group of sedative drugs, others differentiated between sedative drugs, anxiolytics, and analgesics. In explaining their intention, most interviewees particularly emphasized what they want to avoid when administering sedative drugs. We identified four main themes regarding (excluded) intentions: (1) use of sedative drugs to relieve the patient's situation with consciousness reduction as (un)wanted side effect, (2) use of sedative drugs to relieve the situation for the team and/or the relatives, (3) hastening death or shortening life: intention-foresight distinction, (4) avoidance of tranquillising or restraining the patient.

Conclusion: Education in general palliative care should focus more on the differentiation and potential transition from sedation as a side effect to intentional sedation, and on reducing insecurities regarding the latter. Moreover, critical reflexion of indications and intentions in accordance with respective guidelines is needed.

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Abstract number: B-31
Abstract type: Poster

Patients Problems and Needs, when Visiting the Emergency Department of a Tertiary Cancer Hospital: An Observational, Descriptive Study

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Background: Patients with advanced cancer commonly visit the emergency department (ED). Identification of patients with unmet problems/needs could help initiate an appropriate form of palliative care.

Aim: To provide an insight into ED visits of advanced cancer patients at a tertiary oncology hospital.

Methods: 134 adult patients with advanced solid tumors were evaluated. The Hospital's Ethical Committee Approval had been obtained and patients signed a written informed consent; those with extreme fatigue, confusion and/or drowsiness were excluded. Clinical characteristics, the main physical symptom leading to the ED, as well as the unmet problems/needs in other dimensions (psychosocial, practical, freely described by the patients) were recorded. The final outcome was defined by ED physicians.

Results: 64 % were female, with a median age of 59 years (range 46-88). Patients were heavily pre-treated (86.3%). Tumors were metastatic and located mainly at the lung, the gastrointestinal and genitourinary tract, followed by the breast. More than two symptoms were often (92%). Pain (21.0%) and dyspnea (18.6%) were the most common physical symptoms, followed by fever (12%), hemorrhage, ascites and emesis (8%, respectively). Imaging and blood tests were performed to all.
Only 32.8% of patients were hospitalized.
Patients reported an extremely high percentage of anxiety (97%). 74% stated significant lack of information, concerning their cancer. Half of them had unmet spiritual needs and/or practical problems. Almost all patients reported active support from informal caregivers.

Conclusions: Physical symptoms can be adequately treated at the ED, with a decreased rate of hospitalization. Family relationships in Greece are still strong enough to provide support. Palliative care could assist patients in all domains/dimensions; ED shouldn' t be their last 'relief' resort. More communication is warranted, and anxiety, spiritual care and practical needs should be addressed.

Abstract number: B-33
Abstract type: Poster

Development of a Core Outcome Set for the Research and Assessment of Inoperable Malignant Bowel Obstruction

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Background: Malignant bowel obstruction (MBO) occurs when a cancerous tumour blocks the intestines. This can cause pain, nausea and vomiting, and is distressing for patients, caregivers and health care professionals (HCPs). Obstructing tumours cannot always be removed through surgery. It is difficult to draw consistent conclusions about effective non-surgical approaches from existing studies, which use a broad variety of outcome measures.

Aims: To develop a Core Outcome Set (COS) for the research and assessment of inoperable MBO using methodology recommended by the COMET initiative (Core Outcome Measures in Effectiveness Trials).

Methods: A four-phase multicentre study: (1) systematic literature review examining the scope of outcomes associated with inoperable MBO; (2a) interviews with patients, caregivers and HCPs and (2b) rapid review of qualitative literature exploring experiences of MBO; (3) Expert Panel consultation to refine a list of proposed core outcomes; and (4a) a Delphi survey and (4b) consensus meeting with stakeholders to produce the COS. Qualitative data was explored using thematic analysis. Survey data consensus criterion was $\geqslant$70%.

Result: The systematic review identified 83 papers; verbatim outcomes, including individual PROM items, were pooled into 135 standardised terms. Qualitative data suggested that symptom burden and ambiguities in patient-professional communication were key issues, leading to the inclusion of eight further outcomes. After Steering Group/Expert Panel consultation, 82 outcomes were taken forward to the Delphi survey. Stakeholders included patients and caregivers, oncologists, palliative care specialists, specialist nurses, surgeons and dietitians. Consensus was reached on core outcomes for use in research and clinical care.

Conclusions: Outcomes previously used to assess inoperable MBO have lacked consistency and patient relevance. The COS produced by this study will enable a consistent approach to research and clinical assessment.

Abstract number: B-34
Abstract type: Poster

Symptom Profiles of Breast and Gynaecological Cancer Patients Reporting High and Low Distress Levels

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Background: Patient-reported symptoms are routinely collected in a tertiary cancer centre that employs routine distress screening. We hypothesized that patients reporting high distress have a higher symptom burden across different domains.
Aim: To describe and compare symptom profiles of breast and gynaecological cancer patients reporting low versus high distress.
Methods: This cross-sectional review included patients' first visits to outpatient clinics between 16/9/2019 and 31/7/2020. Patients completed the Distress Thermometer (DT) and a 41-item checklist covering problems in five domains: physical, emotional, practical, relationship, and spiritual. High distress is defined by a validated cut-off score of 4 on the DT. Frequently reported symptoms were summarized using descriptive statistics. The prevalence of problems was compared between the low and high distress groups using Chi-squared tests.
Results: We categorized 1386 patients into low (n=876) and high (n=510) distress groups. Overall, patients with high distress reported a higher mean number of problems (5.7 vs. 2.2, $P<0.001$). The prevalence of any physical symptom was higher in the high distress group (88.8% vs. 62.4%, $P<0.001$). Frequently reported physical problems included (high vs. low distress): fatigue (47.5% vs. 20.4%, $P<0.001$), pain (37.1 vs. 17.7%, $P<0.001$), sleep problems (33.9% vs. 15.0%, $P<0.001$), and peripheral neuropathy (31.2% vs. 21.2%, $P<0.001$). For the emotional domain, anxiety was the second most prevalent symptom among the high distress group but was significantly less prevalent in the low distress group (45.7% vs. 13.2%, $P<0.001$).
Conclusion: Besides having a higher symptom burden, breast and gynaecological patients reporting high distress were more afflicted with psychological problems such as worry and anxiety. Distress levels serve as a feasible proxy to distinguish outpatient cancer patients with distinct symptom profiles, allowing subsequent tailoring of supportive care resources.

Abstract number: B-35
Abstract type: Poster

When Do we Call it Intentional Sedation? Daily Dosages of Midazolam in Patients Dying in an Inpatient Palliative Care Service

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Background/aims: Midazolam (M) is widely used in palliative care (PC), for symptom oriented treatment (SOT) as well as for intentional sedation (iSed). It is often challenging to decide whether a treatment shall be labelled as SOT or iSed, in particular when transition is fluid. This analysis attempts to identify differences in 24h-dosing of M between iSed and SOT based on documented treatment intention and to find a delimiter to identify iSed.
Methods: The charts of all patients (n=358) who died on a university PC unit in Germany from 01/2018 to 06/2019 were reviewed. For every day a patient received M, the 24h dosage (in mg) was calculated (M24). The days were classified in three groups to detect a possible transitional onset of iSed: "iSed" for all days of a documented iSed, "t-iSed" for all days preceding an iSed, and "SOT" for all other days. The data was extracted with MS Access and Excel, statistical analysis was performed using SPSS. Mean, standard deviation and median were calculated; Kruskal-Wallis- and Bonferroni-corrected U-test were used to test for difference of median. As a delimiter the 25th percentile of iSed was assumed. Positive (ppv) and negative (npv) predictive values were calculated.
Results: The total number of M24 was 1706. Of the days under review 49 (2,9%) were assigned to iSed, 67 (3,9%) t-iSed and 1590 (93,2%) to SOT. M24 dosages were in iSed (median 16,5; mean 36,2; SD 42,2 mg), t-iSed (5; 7,1; 6,2 mg), and in SOT (3; 4,3; 4,4 mg). The median values differed significantly ($p<0{,}001$). Weighted mean at the 25th percentile was 10,6 mg (iSed). Ppv was 0,4, npv was 0,98.
Conclusions: The median dose of Midazolam in all three groups differed significantly and was also elevated prior to the documented onset of iSed. iSed can be presumed at a dose exceeding 10,6 mg/24h, however ppv is low. These findings should be validated with a different dataset.
Funding: The study is funded by the German Federal Ministry of Education and Research (01GY1702A).

Abstract number: B-36
Abstract type: Poster

Retrospective Analysis of Ketamine Prescribing in Palliative Patients in the Acute Hospital Setting

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Background: Ketamine is an N-Methyl D-aspartate antagonist. Evidence base to date is conflicting, but clinical practice shows that it is an excellent drug choice for carefully selected patients with complex cancer related neuropathic pain.
Aims and objectives: Establish the demographics of the cohort selected. To identify the frequency, dosing regime, duration of treatment and goal of Ketamine prescribed by Palliative Care in the acute hospital setting. To identify if it was used as an adjuvant or a single agent. To establish both benefit and harmful side effects.
Method: Retrospective analysis of patients prescribed Ketamine between April and October 2020, initial dose prescribed, titration to effect, duration of treatment, PRN requirements pre and post introduction, if other adjuvant neuropathic agents were co-prescribed. We recorded each diagnosis, description/site of pain, response in the first 24 hours. Side effects were also analysed.
Results: 32 Ketamine prescriptions charted over 6 month period. 24 female, 8 male all malignant diagnosis, with multiple primary sources. Patients prescribed Ketamine had severe neuropathic pain. There was a reduction in PRN opioid requirements of 60% within the first 24 hours following initiation of Ketamine with a minimal side effect profile. About half required a reduction in their co-prescribed baseline opioid. Average duration of treatment was 10 days. Overall it was very effective and well tolerated for complex "tight space pain".
Conclusion: The 'Burst Ketamine' regime is very well tolerated and highly effective for carefully selected patients. It is very useful for cancer pain where there is central wind up with neuropathic, inflammatory, ischaemic and opioid induced hyperalgesia (OIH). Recent research is mixed on its efficacy for opioid refractory cancer pain, but does suggest that some patients are 'good responders'. Patient selection for future research studies is paramount, severe neuropathic pain and OIH.

Abstract number: B-37
Abstract type: Poster

Cultural and Structural Factors Affecting Physicians' Decision Making and Performance of Continuous Deep Sedation Until Death: An Environmental Context Analysis of Experiences of Physicians

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Background: Physicians encounter many issues concerning decision-making and performance of continuous deep sedation until death (CDS). Previous research has endeavored to grasp the complexity of CDS practice and its relevant factors. As the focus has been particularly centered on (inter)personal factors, little attention has been given to environmental factors i.e., meso and macro level factors.
Aims: To identify which environmental factors affect physicians' decision-making and performance of CDS.
Methods: Context analysis of 47 semi-structured interviews with physicians in Belgium about their experiences with CDS decision-making and practice, using an interpretative thematic approach. Data were collected from January to March 2019 using purposive sampling.
Results: We identified both cultural and structural factors. Cultural factors include 1) moral reservation of the care team and institutions towards CDS, 2) presence of palliative culture, 3) professional stigma among physicians to performing CDS, 4) culture of fear of clinical errors, 5) the ideological signature of care institutions, 6) public misconceptions about CDS, and 7) patients requesting CDS out of fear for death and suffering at the end of life. Structural factors include 1) access to (professional) support in the clinical setting, 2) the use of guidelines and clinical monitoring by the care team, 3) physicians performing CDS to circumvent procedural safeguards of the euthanasia law, 4) lack of knowledge about and training in CDS, 5) the use of different concepts of CDS in the medical field, 6) lack of a clear legal framework on CDS, and 7) time constraints and work pressure.
Conclusion: Environmental factors affecting physicians' decision-making and performance of CDS, are multifold and are centered around culture and structure. To optimize CDS practice permanently and structurally, a whole system approach that takes into account the environmental context seems appropriate.

Abstract number: B-38
Abstract type: Poster

Evaluation of a Community Palliative Care Support Project for People with Advanced Diseases

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Background: Integrating palliative care approach into the community care services is imperative to address the physical, psychosocial and spiritual needs of people with advanced diseases.
Aims: This study aims to examine the effects of community palliative care services on symptom experiences.
Methods: This is a prospective cohort study built on a medical-social collaboration model. People diagnosed with advanced diseases were referred from hospitals to receive comprehensive home-based multidisciplinary support, including professional advice on symptom management, psychosocial support and advance care planning. The Integrated Palliative Care Outcome Scale (IPOS) was used for assessment over six months. The generalised equations model was used for examining changes in symptom experience over time. Ethical approval for this study was obtained.
Results: Forty-eight participants who joined the project between January and December 2020 were included in the analysis. Their mean age was 63.8 years, ranging from 28 to 94. All of them were diagnosed with cancer. At baseline, the three most disturbing symptoms were poor mobility (69.4%), poor appetite (58.4%) and weakness (58.3%). A considerable proportion of them were anxious (80.6%) and depressive (63.9%), could hardly share their feelings with family/friends (83.4%) or received information as wanted (88.9%). Significant improvement were noted in the physical symptoms ($p = .015$), emotional symptoms ($p < .001$), communication/practical issues ($p < .001$) and the overall IPOS score ($p < .001$) over six months. Effect sizes were larger over the first month and in addressing emotional symptoms (0.84) and communication/practical issues (0.86) than physical symptoms.
Discussion: The findings of this study showed that community palliative care service is effective in addressing the psychological and information needs of people with advanced disease, albeit the deteriorating health condition.

Abstract number: B-39
Abstract type: Poster

Palliative Care Patients' Views and Experiences on Complementary and Alternative Medicine (CAM) Use from the Hospice and Palliative Care Perspective

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Background: Complementary and alternative medicine (CAM) includes practices which do not belong to the standard therapy. The use of these methods is not included in Polish palliative care services, however these methods are used within palliative care patients of their own volition.
Aim: The aim of the study was to examine the CAM use among patients undergoing palliative care in Poland.
Methods: A cross-sectional survey was applied. Palliative care patients were asked to complete the semi-structured questionnaire about the usage of CAM. Statistical analysis: Pearson's Chi–square Test.
Results: 433 patients from palliative medicine outpatient clinic were enrolled in the study. The prevalence of CAM use was 44%. Being younger, having higher education, being professionally active, having health care professional relatives or having them abroad predicted CAM use ($p<0,05$). Most often used methods were: vitamin/mineral formulations (53%), herbs (48%), alternative nutrition (28%), marihuana (16%), meditation (15%) and music therapy (14%). The reasons for CAM use, as stated by patients, were: the support of anticancer therapy (71%), decreasing its side effects (27%) and the lack of conventional curative treatment (13%). The greater hope to recover from cancer was one of the benefits from CAM use reported by the majority of patients (58%). The use of CAM in 7% of patients caused withdrawal of the anticancer therapy.
Conclusion/discussion: Despite the fact that CAM does not belong to the conventional therapy, it was used by almost half of the palliative care patients mainly as an aftermath of the applied previously anticancer treatment. Whereas, the CAM use may increase perceived well-being of some patients, it may be harmful in others leading to the discontinuation of the conventional therapy. The real impact of the CAM use on palliative care patients is still not determined and further studies on particular CAM methods should be conducted.
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Abstract number: B-40
Abstract type: Poster

Testing the Waters for a COPD-specific Breathlessness Service in the Netherlands: A Pilot Study

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Background: Refractory breathlessness is a devastating symptom in COPD. Breathlessness services (BS), usually collaborations of palliative and respiratory teams, offer a multidisciplinary approach. In the Netherlands, few palliative teams work in an outpatient setting, and BS do not exist. We were trained by a British BS team and translated their toolkit 'Breathing Thinking Functioning' into Dutch, as a service to be given by a pulmonologist, respiratory nurse and physiotherapist. We chose to deliver the intervention specifically to COPD patients.

Aims: Our question was: is it feasible to perform a randomized controlled clinical trial on the effectiveness of this BS on breathlessness mastery in COPD patients? Feasibility was: 75% of included patients complete the intervention. Secondary purposes: to familiarize the team with giving the intervention; assessing how many sessions per patient were needed; assessing the possible effect (through CRQ, mastery score); assessing patient and professional satisfaction.

Methods: Non-randomized single-center pilot study. Inclusion criteria: COPD; refractory dyspnea; ability to visit the outpatient clinic. During at least 2 visits (including 1 session with a physiotherapist) and 1 telephone call, patients learned non-pharmacological interventions to manage breathlessness.

Results: 22 Patients were included; 19 (90%) completed the intervention. The mean number of clinical visits was 2.2, and 1.7 phone calls per patient. The team was enthusiastic about giving the intervention and felt comfortable doing so. Eight patients (42%) returned a survey; all of those rated the service as excellent and helpful. Average improvement in CRQ score, subset mastery, was 1.6 (clinically important difference 0.5).

Conclusion: It is feasible to design a randomized multicenter controlled clinical trial on the effectiveness of a breathlessness service using the translated Cambridge toolkit, in COPD patients in a respiratory outpatient clinic.

Abstract number: B-41
Abstract type: Poster

Assessing the Relative Impact of Enhanced Supportive Care on Patients' Quality of Lives between Primary Tumour Diagnoses

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Background: We previously published a case control study of the impact of Enhanced Supportive Care (ESC) on quality of life and other patient outcomes. This was a mixed cancer sample and whilst benefits were seen overall in quality of life scores, little is known about how this varies between patients with different primary tumour diagnoses. Knowing which patients derive the greatest benefit from this service is important in shaping future services using limited resources.

Aim: To describe variation in quality of life benefits for patients attending ESC by primary tumour group

Method: From April 2019-March 2020 we undertook a prospective service evaluation comparing outcomes for patients accessing ESC. Purposive sampling was used to select patients belonging to specific primary tumour groups: Breast, Upper GI, Head and Neck, Melanoma, Lower GI, CNS and Sarcoma. Quality of life data was collected using IPOS. Change over time was measured using a single-system design. Non parametric data was analysed using Mann-Whitney U Test.

Results: 275 patients' IPOS scores were analysed. For the whole mixed cancer cohort, IPOS revealed statistically and clinically significant reduction in severity scores for pain, weakness, appetite, anxiety and mobility after their first appointment with ESC. In subgroup analyses, the greatest overall score improvement was in patients with breast, lower GI and upper GI cancers. The greatest median effect was seen in patients with breast cancer who also reported improvements in more physical symptom domains than any other group. Patients with head and neck cancers had no overall quality of life benefit and no statistically significant improvement in pain control.

Conclusion: ESC benefits were not equivalent across primary tumour groups after a first appointment. Patients with breast, lower GI and upper GI cancers benefitted most, whilst patients with head and neck cancer benefitted least. Further work is needed to describe the cause of this variation.

Abstract number: B-42
Abstract type: Poster

Intentional Sedation to Ease Suffering. An Innovative Terminological Approach to Sedation in Palliative Care

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Aim: Terminology concerning sedation practices in palliative care has been criticised as being too heterogeneous, vague and difficult to apply. Unclear terminology has negative impact on reliability of quantitative data and ethical discourse about the practices and is relevant for clinical practice. We present a systematically constructed and justified terminological proposal intended to clarify the concept of sedation for clinical practice, research and for ethical and legal assessment.

Design, methods and approach taken: Based on logical and analytical considerations and informed by a systematic review of definitions in guidelines, we stepwise developed definitions of key terms. Drafts were discussed and refined as part of an iterative process within an interdisciplinary research group with experts from palliative care, ethics, law and philosophy of medicine and according to feedback from experts from outside our study group.

Results: We propose defining core terminology stepwise in a precise way, separating matters of terminology (i.e. what is the practice) from matters of good practice (i.e. when and how to use it). As core terms, we define reduced level of *consciousness* as a level of consciousness scoring <0 on the RASS-PAL scale, *sedation* as the result or process of sedating and *intentional sedation* as the result or process of sedation a patient as a means of achieving a previously defined treatment goal. Further terms of the proposal are *light, deep, temporary sedation* and *sedation until death*.

Conclusion / lessons learned: This terminology facilitates the precise phrasing of specific aims (e.g. to reduce suffering), indications (e.g. refractory and intolerable suffering) and rules for good practice (e.g. appropriate medication). Thus, it allows for variation in practice recommendations without affecting core terms relevant for describing and evaluating practices of sedation in palliative care.

Abstract number: B-43
Abstract type: Poster

Efficacy of Rectal Administration of Pregabalin in a Rat Neuropathic Pain Model

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Background: Pregabalin is used to relieve neuropathic pain. Patients receiving palliative care cannot take medicine orally in some situations such as the end stage of a disease. Since there is no intravenous or suppository form of pregabalin, pain controlled by pregabalin might worsen if patients cannot take pregabalin orally. If a suppository form of pregabalin is shown to be effective, it would be useful in a palliative care situation.
Aims: The aim of this study was to determine the efficacy of rectal administration of pregabalin for neuropathic pain using a rat model.
Methods: We used the partial sciatic nerve ligation model for neuropathic pain in rats. Rats were divided into 3 groups (n=6 in each group) in which 6 mg/kg or 12 mg/kg of pregabalin was administered rectally with 0.2 ml of saline or only 0.2 ml of saline was administered (control group). Before and at 30, 60 and 120 minutes after administration of pregabalin, we evaluated mechanical hyperalgesia by testing the escape threshold using von Frey filaments and spontaneous pain by a dynamic weight-bearing test. The data were analyzed by two-way ANOVA followed by the Tukey post hoc test.
Results: At 120 minutes after rectal administration of pregabalin, the escape threshold for mechanical stimulation was significantly increased compared with that in the control group (P=0.03 in the 6 mg/kg group, P=0.0003 in the 12 mg/kg group). The weight ratio of ipsilateral/contralateral hind paws and the weight ratio of the diseased hind paw to the total weight were significantly increased in the 12 mg/kg group at 60 minutes after administration compared with those in the control group (P=0.0011 for the weight ratio of ipsilateral/contralateral hind paws and P=0.019 for weight ratio of the diseased hind paw/total weight).
Conclusion: The results was suggested that rectal administration of pregabalin improved neuropathic pain in rats.
This work was supported by the JSPS KAKENHI Grant number 16K09236.

Abstract number: B-44
Abstract type: Poster

Deprescribing at End-of-Life: A Review of Potentially Inappropriate Medications in the Oncology-palliative Population

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Background: Palliative care patients are often prescribed medications for primary/secondary prevention and symptom control, along with disease-modifying treatments (DMT). This can result in, polypharmacy, an increased risk of adverse events, significant tablet burden and reduced compliance, negatively affecting quality of life (QoL). A validated tool supporting deprescribing in the Oncology-Palliative
population is the 'Onc-Pal deprescribing guideline', identifying medication classes suitable for discontinuation.
Aims and Objectives: To evaluate discontinuation of potentially inappropriate medications (PIM) 7 days prior to death, in cancer patients referred to the hospital palliative care team (HPCT).
Methods: Retrospective chart review. Proforma devised using 'Onc-Pal deprescribing guideline' for data collection. Inclusion criteria: Adult patients, malignant diagnosis, known to the HPCT, having died in hospital over a duration of six months. Patients who died in the Intensive Care Unit or within seven days of hospital admission were excluded.
Results: 58 patients eligible. 33 recieving DMT during acute hospital episode. 54 had metastatic disease, 8 patients were not prescribed PIM. 147 PIM prescribed in the last week of life, average number per patient was 2.5 with 3 patients were prescribed a maximum of 7 PIM. The commonest PIM was Proton Pump Inihibitors. 73 PIMs were discontinued, with 51% discontinued 1 day prior to death.
Nurses were unable to administer 95 PIMs during the week prior to death, e.g. 'route not available', 'condition related'.
Conclusion(s): 50% of PIM discontinued prior to death. Barriers to deprescribing may have been encountered or an unanticipated clinical deterioration occurred as well as Fear at junior doctors to 'stop' medications. This study is an important reminder to
clinicians to regularly review medications and discontinue PIM with no benefit, therefore minimising the risks and burden of multiple medications.

Abstract number: B-45
Abstract type: Poster

Pain Assessment of Palliative Care Patients within the Inpatient Setting: A Systematic Scoping Review of Barriers and Facilitators

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Background: Pain is one of the most prevalent symptoms in end-of-life patients. A pain-free death is a priority for patients, families, and a key quality indicator for end-of-life care provision worldwide. Pain assessment is the foundation of effective pain management, however, this can be challenging due to the complex, multi-faceted, and subjective nature of pain as well as physiological changes in the end-of-life trajectory.
Aims: To identify the barriers and facilitators of pain assessment in the inpatient settings of specialist and non-specialist providers.
Methods: The systematic scoping review searched five electronic databases, seven websites, and three peer-reviewed journals. Original (and synthesis) studies describing barriers and facilitators to pain assessment among patients of all ages, their families, and healthcare professionals were included. Studies were screened and abstracted independently by two reviewers and discrepancies discussed with a third reviewer. Data abstraction and summary is ongoing. Themes and subthemes were identified from qualitative papers.
Results: A total of 649 references were screened and 117 full text articles were read for data abstraction. Limited studies covered non-cancer patients and the last days of life. We identified three themes acted as barriers and facilitators, these are: knowledge, attitudes and beliefs, and systemic factors. Pain management was never solely informed by the use of pain assessment scales, the use of validated pain scales were mainly included in health technology assessment studies.
Conclusion / Discussion: Unrelieved pain affects the physical and psychological state of patients and their families, however, assessing pain at the end-of-life can be challenging, especially in patients who have difficulties with communication. This review highlighted key barriers to optimal management of pain in end-of-life care.

Abstract number: B-46
Abstract type: Poster

Patient and Clinician Experiences of Inoperable Malignant Bowel Obstruction: A Qualitative Study

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Inoperable malignant bowel obstruction (IMBO) affects people with some advanced cancers. It is a distressing complication of cancer and has a profound effect on quality of life. However, few studies explore in-depth experiences of IMBO and its management. Therefore, our understanding on patient meaningful clinical outcomes to inform clinical practice and research, is poor.

To ascertain experiences of patients and clinicians, to identify patient-relevant outcomes.

Semi-structured interviews (N=26) with patients (n=7) and clinicians (n=19). Interviews were transcribed verbatim and data subjected to thematic analysis. The study is part of a larger project, (Research Assessment of Malignant Bowel Obstruction – RAMBO) to inform a core outcome set for IMBO in clinical practice and research.

Findings highlighted uncertainty surrounding IMBO management and the different experiences of each patient. IMBO was associated with detrimental symptoms, such as pain (most dominant), vomiting, nausea and fatigue. Patients and clinicians had to negotiate between a range of perspectives on which treatments would be most effective, with variable success in symptom reduction. This complex decision-making, and multi-professional involvement could cause uncertainty and confusion for patients. Added to that the indication of an IMBO diagnosis (i.e. cancer treatment is put on hold, or no longer an option) the stakes for these patients were high, and acutely felt.

IMBO is a highly challenging condition to manage; finding ways to maximise quality of life (sense of normality, family, work) proves difficult and time to get this right is short. Symptoms are severe and have a devastating impact on patients' physical and emotional wellbeing. Multiple factors involved in decision-making and variable responses to treatment, were a source of frustration for both patients and clinicians, as well as the uncertain trajectory and iterative decline, which was interspersed with devastating disappointments.

Abstract number: B-48
Abstract type: Poster

Development of a Rules-of-Thumb Tool to Identify and Address Discomfort and Distress in Hospitalised Older Adults with Dementia

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Introduction: Up to 42% of acute hospital inpatients have dementia. This can make it more difficult for patients to communicate their needs, this in turn may lead to distress and agitation. The aim of this study is to explore the development of a set of rules of thumb to help better identify and ameliorate distress and discomfort in patients with dementia in acute hospitals who are not be able to communicate their needs.

Methods: A series of existing clinical and observational methods were used to measure various aspects of the experience of hospitalised inpatients with dementia, and staff working with these patients on wards. Using the results of these measures, a set of rules of thumb were developed through co-production with professionals, carers and people living with dementia. Data from co-production sessions were combined by the research team to build a set of rules of thumb.

Results: The hospital study highlighted pain, delirium, physical discomfort, emotional wellbeing, environment and communication as key elements of discomfort. Following co-production, stakeholder groups identified a number of ways to address these discomforts. The research team compiled and formatted these approaches into a set of rules of thumb for use in acute hospitals. These take the form of simple, easy-to-use diagrams.

Conclusions: Signs of distress and agitation are common in hospitalised persons with dementia. Patients are often disoriented, which impedes communication of needs. This also has a high burden on staff, as many behavioural and psychiatric symptoms of dementia are experienced daily on wards. By developing a set of rules of thumb through co-production with stakeholder groups, distress and discomfort may better be able to be identified and addressed in acute hospitals.

Abstract number: B-49
Abstract type: Poster

Audit: To Assess if Un-necessary Medications Are Discontinued in Patients Imminently Dying

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Background: The goal of end of life care (EOLC) is a good and dignified death. There is a need at EOL to rationalise medications so that they support this goal, especially since EOL is associated with increased medication burden and adverse drug events. Palliative medicine is a liaison service in our hospital, and thus rationalisation of medication is the role of the primary team.

Aim: To assess if unnecessary medications are discontinued in the last days of life of patients referred to palliative medicine for EOLC. The Irish Health Service Executive (HSE) guidelines were consulted: *'Care in the last hours and days of life'*. These documents advise to consider stopping any mediation that does not confer comfort or alleviate symptoms/distress unless there is a good reason to continue.

Methodology: Patients referred to palliative service for EOL care over a 2 week period were reviewed for suitability. Those who were in the last days of life were selected for inclusion. Their medical notes and prescription charts were reviewed and we recorded if regular medications were rationalised.

Intervention: The guideline and results were discussed with the palliative care team. The intervention involved a written entry in the medical notes advising and thus prompting the primary team to rationalise medications.

Results: 1*st* Audit cycle-of the 10 who met the criteria only 50% had their regular medications rationalised.

Re-audit: Three weeks after the intervention, over a 2 week period, 10 charts were reviewed which revealed improved compliance of 70% with guidelines.

Conclusion: There is a suboptimal adherence with the guidelines. A teaching session is planned to address this educational need. This session will focus on the HSE guideline on *care in the last hours and days of life* and also provide information on validated tools which help rationalise medications at EOL and other methods of delivery of necessary medications. After this session there will be a re-audit.

Abstract number: B-50
Abstract type: Poster

Rapid Program–effectiveness of Paracentesis for Malignant Ascites at Different Time Points

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Background: Paracentesis is the most commonly used treatment to manage malignant ascites, and has been shown to provide relief in up to 90% of patients.
Aim: Examine the effectiveness of paracentesis at different time points post paracentesis.
Methods: This is part of an international, multisite, prospective observational consecutive cohort study that assessed symptoms (abdominal pain, abdominal distention, fatigue, anorexia, nausea, breathlessness) prior to paracentesis (T0) and 4 hours post paracentesis (T1), 4-24 hours post paracentesis (T2), 24 hours to 7 days post paracentesis (T3) using National Cancer Institute Common Terminology Criteria for Adverse Events.
Results: At baseline, data for 107 (M:F 55:52) patients were completed. The median age was 69 (IQR 60.0-76.0) years old. About half of patients (50.5%) had an Australian Karnofsky Performance Score (AKPS) of 40-50, and 32.7% with an AKPS 60-70. The median serum albumin was 25g/L. The most common cancer was pancreatic cancer (20.6%).
The primary indication for paracentesis was acute symptomatic treatment rather than diagnostic or routine paracentesis
At baseline, abdominal distention was the most common symptom (91%) and was also the most common severe symptom (25.2%). The next most common severe symptom was fatigue (22.4%) and anorexia (16.8%). By T1(n=96), severe abdominal distension, fatigue, and anorexia was reported in 1.9% ,8.7% and 10.6% of patients respectively. By T3 (N=85), abdominal distension, fatigue and anorexia had decreased to 0%, 3.5%, and 1.2% respectively.
In this cohort, the following adverse events occurred: peritoneal infection (1.9%), intra-abdominal haemorrhage (0.9%), skin infection (0.9%), and bowel perforation (0.9%).
Conclusion: Clinicians generally reported benefit with some harms. Some symptoms resolved quickly, within hours of the paracentesis, and the benefits lasted for more than a week. Paracentesis appears to be an effective procedure to manage ascites and its associated symptoms.

Abstract number: B-51
Abstract type: Poster

Continuous Subcutaneous Infusions in Palliative Care - A Literature Review

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Background: Continuous Subcutaneous Infusions (CSCIs) or syringe driver/pumps are used in the palliative care setting to deliver a drug (or combination of drugs) over a measured period of time subcutaneously to patients for whom the oral route is not possible for a number of reasons.
Aim: To provide a critical evaluation of the available literature regarding the use of CSCIs in palliative care.
Methods: A systemic literature review was carried out in March 2020. Databases searched included Medline, Embase, CINAHL and Cochrane.
Results: The literature review revealed 11 original articles that were applicable to this subject that included systematic reviews, qualitative studies and opinion pieces. These revealed evidence relating to indication for the use of CSCI when the oral route is not possible, the management of site reaction and the importance of education to all staff using syringe pumps. It was also highlighted that clear, concise communication between healthcare professionals, patients and those who are important to them is essential due to negative connotations associated with CSCIs. This literature review highlighted that at present there is lack of appropriate guidance/evidence that supports anticipatory prescribing of CSCIs.
Conclusion: While the use of CSCIs is common place in the palliative care setting for symptom management when the oral route is no longer available, there is a lack of evidence that supports anticipatory prescribing of medication delivered via this route. It was also highlighted that there remains negative connotations associated with the use of CSCIs. Further work is required in both areas.

Abstract number: B-52
Abstract type: Poster

A Clinical Case of Central Pontine and Extrapontine Myelinolysis

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Background: Osmotic demyelination syndromes consisting of Central pontine myelinolysis (CPM) and extrapontine myelinolysis (EPM) are rare neurological disorders characterised by damage to areas of the brain following abrupt osmotic fluctuations. These osmotic- driven neurological sequalae are caused by rapid correction of hyponatremia which causes large shifts in intra-cellular fluids leading to demyelination of neurons. Risk factors which pre-dispose to CPM include chronic alcoholism, malnutrition and hypokalaemia. Clinical course often consists of a biphasic phase and outcome is highly variable with many patients developing neurological complications.
Case presentation and management: A 39 year old female presented with reduced level of consciousness and hyponatremia on a background of excessive alcohol intake. Despite gradual correction, the sodium levels rose dramatically from 97mmol/L to 116mmol/L over 12 hours. Patient's neurological condition deteriorated rapidly requiring escalation to intensive care unit and intubation. Initial Computed tomography (CT) scans of the brain did not report any intracranial abnormalities. A subsequent Magnetic resonance imaging (MRI) scan of the brain confirmed diagnosis of central pontine and extrapontine myelinolysis. Patient continued to receive supportive care but unfortunately made no neurological recovery following trial off sedation. Patient developed complications including aspiration pneumonia and oral secretions and began to approach end of life (EoL). Referral made to palliative care team and patient required daily titration of syringe driver to control symptoms at EoL.
Discussion: This case conveys complexity of cases with osmotic demyelination syndromes. The neurological complications because of the demyelination process affecting different parts of the brain can cause high symptom burden at EoL and require input from specialist palliative care team to provide sustained symptom control.

Abstract number: B-53
Abstract type: Poster

Retrospective Study of Opioid Use in Cancer Patients who were Referred by Home Physicians or Admission to the Palliative Care Unit

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Aim: The palliative care unit (PCU) of our hospital has 24 beds and accepts cancer patients who have been treated at cancer hospitals or at home. With improvements in home medical care, symptom control among home cancer patients is also progressing. However, when it is sometimes difficult to control the symptoms, such as with severe cancer pain at home, these patients might be referred to the PCU; thus, it is necessary to understand the actual use of opioids at home.

Methods: We retrospectively analyzed 400 cancer patients who died in our PCU during the two-year period from April 2018 to March 2020. Among them, 74 (18.5%) were referred for hospitalization by their home physicians. We investigated and examined the history of opioid use before and after admission.

Results: Out of 74 patients, 38 were male and 36 were female; with an average age of 75 ± 13 years (40-95 years). Thirty-five (47%) were prescribed regular strong opioids by their home physicians, and 18 were taking oral medication (hydromorphone 6 cases, oxycodone 4 cases, methadone 4 cases, tapentadol 3 cases, morphine 1 case). There were 13 cases of fentanyl patch and 4 cases of continuous subcutaneous injection (one case each of morphine, hydromorphone, fentanyl and oxycodone). Of the 39 patients (53%) who were not prescribed strong opioids by their home doctors, 23 (59%) received strong opioids after their admission to PCU.

Conclusion: Before admission to PCU, various opioids were already used properly, and some patients received continuous subcutaneous injection of opioids. However, some patients had not received opioids despite experiencing uncontrolled severe pain. Opioids may be initiated after admission to PCU due to the progression of the condition. It is important to understand the characteristics of the various opioids and to know how to use them properly. Thus, it is essential to advance pain control in both hospitals and at home while supporting the patients together.

Abstract number: B-54
Abstract type: Poster

The terminal phase in Parkinson's Disease: A Mixed Methods Systematic Review

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Background: Extending palliative care to people with Parkinson's disease (PD) has been a priority over the last decade. Whilst there has been an increase in research into advance care planning and early integration of palliative services, less is known about the dying phase in this cohort.

Aims: To systematically review and synthesise the current literature describing the occurrence of and management of symptoms in the terminal phase of PD.

Methods: Searches of MEDLINE, Embase, CINAHL, PsycInfo and Web of Science from 1990 to 2020 were conducted, with further citation, reference and grey literature searches. Eligible papers reported original research of any study design, published in English in peer-reviewed journals. Thematic synthesis of qualitative articles and narrative synthesis of quantitative articles were integrated to produce the final analysis. Quality was assessed by two authors using Gough's Weight of Evidence (WoE) framework.

Results: 4282 articles were reviewed and 18 met the inclusion criteria. Retrospective case record reviews (n=7), case studies (n=7) and interviews (n=4) were included. The majority of articles were of poor quality, with 45% rated as 'low quality' WoE, and thus wider extrapolation of the results is restricted.

Professionals found recognition of the terminal phase difficult, and palliative care services appear underutilised. Challenges include titration of dopaminergic medication, leading to premature termination or incorrect dosing of dopaminergic medication. Nonetheless, there is good awareness of the need to avoid D2 antagonists in the management of nausea and psychiatric symptoms.

Conclusion: More primary research is needed to describe the terminal phase of PD, in both the hospital and community setting, in order to increase the evidence base for symptom management, strengthen service provision and improve patient experience.

Abstract number: B-55
Abstract type: Poster

Primary Care and Nursing Home Teams' Perceptions of Symptom Management and Interdisciplinary Collaboration in Palliative Care: A Cross-sectional Survey Study

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Background: Primary care and nursing home teams provide palliative care. To meet the needs of patients and families, systematic symptom management supported by interdisciplinary collaboration is required.

Aims: To explore the current practice of symptom management and interdisciplinary collaboration.

Methods: A cross-sectional survey study in a convenience sample of primary care and nursing home teams. Symptom management was operationalized in 3-steps: identification, palliative reasoning and communication. Interdisciplinary collaboration was measured by the Modified Index of Interdisciplinary Collaboration (1.0 highest perception, 5.0 lowest). Descriptive statistics were used for analysis.

Results: Out of 5 district teams from 2 home care organizations, general practitioners, chaplains, paramedics, and 11 nursing home teams from 5 nursing homes 114 professionals participated: 50% nurse assistants, 22% RN, 16% paramedics, 5% physicians, 4% dieticians, 2% chaplains. The palliative phase was not marked by 27% of them; if the life expectancy of a patient was estimated 56% did not share this within the team. Most participants investigated symptoms, 32% sometimes/never explored the psychological and social dimension nor the spiritual dimension (50%). For identified symptoms, the cause was unknown for 25% of participants and 20% did not know which intervention to apply. During the start of care, half of the participants was not involved in clinical decision making, during the process involvement ameliorated. Overall, the communication with patients was perceived as good. Nursing home teams had a slightly higher perception of collaboration (2.3 vs. 2.6)

Conclusion: Although collaboration is mostly perceived as positive in primary care and nursing home teams, interdisciplinary collaboration seems not to be optimal during the identification, analysis of symptoms and decisions on interventions.

Funding: Netherlands Organization for Health Research and Development

Abstract number: B-56
Abstract type: Poster

Variations in Practice: Paracentesis in Malignant Ascites

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Background: Paracentesis is the most commonly used treatment to manage malignant ascites, and has been shown to provide relief in up to 90% of patients.
Aim: To examine the variations in the management of malignant ascites in a palliative care context.
Methods: This is part of an international, multisite, prospective observational consecutive cohort study that assessed patients' symptoms and paracentesis management.
Results: A total of 107 (M:F 55:52) patients were observed. The median age was 69 (IQR 60-76.0) years old, and the majority (n=46, 43%) were in the deteriorating phase. The median serum albumin was 25g/L.

Fifteen and 9 patients were receiving frusemide and spironolactone respectively. Most patients (87.9%) had their paracentesis in a facility with a paracentesis protocol.

Paracenteses were performed in acute hospitals (49.3%), palliative care units (40.2%) and in the outpatient clinic (7.5%). The majority of paracentesis were done in the radiology department (65.4%), with a smaller number done blind (14.0%). Most patients (57%) had a pigtail catheter inserted, but 21.5% patients had a tunnelled or indwelling catheter inserted. About 40% of the patients had previous paracentesis in the last 3 months.

A median of 5L of ascitic fluid was removed. About 30.8% of patients had intravenous fluid or albumin replacement, with 26.9% of patients receiving 20% albumin. Two percent of patients received fluid replacement because they were symptomatic, while others received fluid replacement routinely because of renal impairment (19.2%), low blood pressure (4.8%), and the volume of ascites drained (3.8%).

Most paracenteses (32.7%) ceased according to the protocol, followed by spontaneous cessation of drainage (21.0%) and drain malfunction (7.4%).
Conclusion: Ideally, best practice should be guided by evidence based-medicine. There appears to be variation in the management of paracentesis in the setting of its insertion, fluid replacement, and cessation.

Abstract number: B-57
Abstract type: Poster

Conceptualising Effective Symptom Management in Palliative Care: A Novel Model Derived from Qualitative Data

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Background: A key aim of palliative care is to optimize management of troubling symptoms. Pain, breathlessness and fatigue are challenging symptoms to manage in advanced disease. Specialist palliative care leads to better symptom management. Factors contributing to successful symptom management in hospice care have not been explored.
Aim: We aimed to understand what facilitates effective symptom management in hospice-delivered palliative care.
Methods: Qualitative semi-structured focus groups and interviews were conducted with 61 participants (doctors, nurses, healthcare assistants, physiotherapists, occupational therapists, complementary therapists, social workers, chaplains) at 5 hospices. Recruitment was May to November 2019. Interviews were audio-recorded and transcribed. Data was analysed with a grounded theory approach. A thematic framework was developed to facilitate exploration of transcripts. Conceptual mapping was conducted alongside to explore how emerging themes interacted.
Results: A novel qualitative data-derived model of effective symptom management in palliative care was developed. The model is based upon a logical sequence of interacting domains of engagement, partnership, decision and delivery. Each domain was influenced by a combination of patient, family, professional and service provision factors. Patients and families lacked understanding about symptom management. A holistic approach by a co-ordinated team, including support to recognise and minimise psychological distress was a facilitator. Families were key to effectiveness of symptom management interventions. Barriers to effective symptom management included team discordance and lack of clarity about role boundaries.
Conclusion: An effective symptom management strategy should focus on engagement, partnership, decision, and delivery with patients and families.

Yorkshire Cancer Research, *RESOLVE: Improving health status and symptom experience for people living with advanced cancer*

Abstract number: B-58
Abstract type: Poster

Evaluation of Morphine and Oxygen Use in Terminally Ill Patients with Dyspnea in Brazil

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Background: Dyspnea is a frequent symptom in patients facing life-limiting diseases, causing intense suffering, especially at the end of life. However, at the end of life, dyspnea is poorly identified and under-treated symptom.
Aims: To evaluate the morphine and oxygen use in patients with dyspnea at the end of life in a general hospital and an oncological hospital in Brazil.
Methods: This retrospective cross-sectional study included all adult patients selected for end-of-life and palliative care who reported dyspnea at the last 24 hours of life died from July to December 2018 at Hospital Regional da Asa Norte, Brasília, Distrito Federal, Brazil, and at Hospital Santa Rita, Porto Alegre, Rio Grande do Sul, Brazil. Criteria for end-of-life and palliative care were defined according to the Prognostic Indicator Guidance of Gold Standards Framework (PIG-GSF). Deaths that occurred in ICU and operating rooms were excluded.
Results: During the study period, 296 patients had criteria for palliative care. From these, 230 patients reported dyspnea in the last 24 hours of life (77.7%). The palliative care need was identified in less than a third of the cases (28.7%). Mean age was 67.5±14.8 years and 55.6% were male. Neoplasia was the main primary diagnosis (86.1%). Morphine use was identified in 168 patients (73.0%) and Oxygen therapy in 77 patients (33.5%). The oncological hospital uses more morphine (84.5% vs 15.5%; $p \leqslant 0{,}001$) and less oxygen (39.0% vs 61.0%; $p \leqslant 0{,}001$) than the general hospital.
Conclusions: Dyspnea is a prevalent symptom at the end of life. Despite its proven efficacy in relieving respiratory distress, morphine was not used in all patients who reported dyspnea, mainly in the general hospital. Almost all end-of-life dyspnea patients in the general hospital were using oxygen therapy, which may indicate an overestimation of its benefits, underestimating its possible side effects, as well as increasing treatment costs.

Abstract number: B-59
Abstract type: Poster

Assessment and Management Plan of Oral Care at End of Life: A Clinical Audit

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Background: Oral care is an important task when providing end of life (EoL) care to patients. Careful daily assessments of the oral mucosa, tongue and the lips are necessary to ensure patient's mouth has intact mucosa, is clean, moist and pain-free.

The management of dry mouth should be included in a patient care plan. The HSE has published a clinical guidance and evidence on Non-Pharmacological Care in the Last Hours or Days of Life (2020) which discusses mouth care as an important part of physical care with the need to regularly moisten oral cavity with sips of water/ water-based gels emphasised.

Aim(s): To assess examination and management plan for oral care of patients at terminal phase of their lives who are known to the hospital specialist palliative care team. Standard(s); 100% compliance.

Methodology: The medical notes and regular prescription charts of identified patients at EoL were reviewed over five days to examine if oral assessment and plan had been documented. 11 regular prescription charts and notes were reviewed, an assessment and care plan documented in 76%.

Intervention: Relevant stakeholders in the specialist palliative care team were informed of the initial results and advised on recommendations.

Recommendations: On review of patient at EoL, the prescriber should document artificial saliva replacement in the regular prescription chart. When reviewing patients check oral area for dryness, evidence of candidiasis and/or ulceration. Document findings in notes.

Re-Audit: This was done 2 weeks after the initial audit. 8 regular prescription charts and medical charts were reviewed over 5 days and there was 100% compliance.

Conclusion: It is important that oral care is included in care plan for every patient at EoL. Documentation of artificial salivary replacements in the patient's prescription sheet may aid the implication of this care plan especially in an acute hospital setting.

Abstract number: B-61
Abstract type: Poster

Retrospective Analysis of Methadone Prescribing Trends in Palliative Patients in an Acute Hospital Setting

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Background: Methadone is a synthetic mu opioid analgesic that possesses n-methyl-d-aspartate (NMDA) activity, and a d-isomer that acts centrally on cough. Methadone has a complex pharmacological profile with many safety concerns and thus practitioners are reluctant to use it. Recent evidence suggests that methadone has a specific role in the management of complex pain with suspected tolerance and/or opiate induced hyperalgesia (OIH).

Aims and objectives: To evaluate the rationale for methadone prescribed by palliative care in an acute cancer centre setting and establish demographics of this cohort.

Methods: A retrospective analysis of patients prescribed methadone between March 2020 and February 2021 was performed. Patient age, sex, primary diagnosis, indication for methadone, and their prescription charts were reviewed. Methadone used as analgesic was classified as adjunct when co-prescribed with 'other' opiate or maintenance if used as single agent. Documented evidence of use for neuropathic pain, tolerance or suspected OIH was recorded.

Results: Nineteen patients were prescribed methadone, 9 female, 10 male. Methadone was found to effectively treat 'intractable cough' and the majority had diagnosis of lung carcinoma/metastases.

Ten were prescribed methadone for pain, the majority of this cohort had metastatic cervical cancer or pelvic metastases. All cases had neuropathic pain plus/minus suspected opioid tolerance or OIH. Mean dose for cough 5mg/24hrs and mean dose for pain 16mg/24 hours. Methadone used for pain, was predominantly used as an adjuvant and was effective as represented by decreased requirement for both prn medication and opiate dose escalation.

Conclusion: Methadone is an effective, well tolerated centrally acting antitussive. Recent research on OIH revitalises methadone as a co-analgesic for complex pain and/or eliminate tolerance, for appropriately selected cancer patients. It can also be used in combination with other opioids.

Abstract number: B-62
Abstract type: Poster

Sedation at the End of Life: What Are the Risks Mentioned in Guidelines on Palliative Sedation?

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Background/aims: Sedation (intentional sedation, palliative sedation) offers great benefits for patients at the end of life, who experience suffering that cannot be alleviated in any other way. When considering this treatment option, also possible risks have to be taken into account. Up to date, no concise overview exists, which risks of sedation have to be considered within palliative care.

Methods: These results are part of a systematic review of official guidelines on palliative sedation. The search includes documents published between 2000 and 2019 and was performed in 2019 in pubmed, google scholar, Scopus and as hand search online. The content of the guidelines was coded using MaxQDA software. A narrative synthesis of all references to potential risks of sedative treatment or palliative sedation was performed.

Results: In total, 459 documents were retrieved. After analysis, 31 guidelines were included in further qualitative synthesis. In 25 documents, detailed risks are indicated, 4 guidelines only state that risks exist, in 2 no risks are mentioned. In 7 of the guidelines, the risk of hastening of death is explicitly mentioned. Other indicated risks contain respiratory depression; circulatory depression; aspiration; agitation as paradox reaction; delir; loss of autonomy and communication capabilities and of the ability to eat and drink; obstruction of the upper airway; incomplete alleviation of symptoms; in case of planned intermittent sedation: that initial level of consciousness cannot be regained; risks for surrogates: feelings uncertainty, alienation, stress.

Conclusions: The relevant risks of sedative treatment are not integrated in all official guidelines. This may impact clinical practice. Hence, the development of information standards including possible risks for consent discussions on sedation with patients and surrogates may be beneficial.

Funding: Funded by the German Federal Ministry of Education and Research (01GY1702A).

Abstract number: B-63
Abstract type: Poster

Everyday Memory and Processing Alteration in Patients with High-grade Glioma after Radiotherapy: A Mixed Method, Public Survey

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Background: Symptoms experienced due to high-grade glioma (HGG) and its treatments can negatively affect patient quality of life. Cognitive changes can be especially difficult to understand as they are more challenging to quantify and describe.

Aims: Primary: to better understand the areas of cognition altered in patients with HGG after radiotherapy (RT). Secondary: to establish an understanding of how patients and their families may perceive changes.
Methods: A mixed method, public survey of stakeholder experiences of everyday cognitive functioning, asking patients, their family and friends (FF), and healthcare professionals (HCP) how often they experience/ observe difficulty with daily mental tasks after RT. Likert scales were coded 1 to 5. For patients and FF, 1 represented 'much less often' and 5 'much more often'. For HCP 1 represented 'never' and 5 'very frequently'. Responses were descriptively analysed. Open-ended questions were thematically analysed.
Results: 143/148 participants (97%) completed the survey (patients n=91; FF n=46; HCP n=6). Many situations received responses ranging 1 to 5. Patients, and FF, reported mean responses to be above 3 (same as before) for all questions, ranging from 3.4 to 4.3. HCPs reported observing patient difficulty in all daily tasks. Free text responses show that patients and FF acknowledged a strain on daily living, with recurrent themes including patient reliance on others and a decline of emotional wellbeing of patients. Distinctions between responses show FF focus more on patient personality changes and how patient-family interactions are negatively affected. Patients describe changes first-hand, with emphasis on coping mechanisms.
Conclusion Decline may be experienced across all cognitive domains. This negatively impacts both patients and those around them. Whilst both express this, both give unique insight as to how this is experienced. Both perspectives should be accounted for when assessing a patient's cognitive state.

Abstract number: B-64
Abstract type: Poster

Retrospective Analysis of Phenobarbitone Prescribing in Palliative Patients in the Acute Hospital Setting

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Background: Phenobarbital is classed as a sedative anti-epileptic that has an overall effect of depressing the central nervous system. It has a dual action of prolonging the opening of chloride channels on GABA receptor complex as well as inhibiting glutamate transmission at non-NMDA receptor channels. Phenobarbitone is licenced for treatment of epilepsy. In palliative care phenobarbitone is considered in patients with seizures and those with terminal agitation not responding to high dose benzodiazepines and anti-psychotics.
Aims and objectives: To identify the frequency, duration of treatment , dosing regime and goal of phenobarbitone prescribed by specialist Palliative Care team in the acute hospital setting and identify demographics of this cohort. Another aim to identify whether it was used as an adjuvant or a single agent and establish any side effects.
Method: A Retrospective analysis of patients prescribed phenobarbitone between May 2020 and February 2021 was carried out. We identified initial dose prescribed, titration to effect, duration of treatment, PRN requirements pre and post introduction. We recorded each diagnosis and response in the first 24 hours. Side effects were also analysed.
Results: 46 phenobarbitone prescriptions were issued in the 9 month period. 25 were female and 21 were male. Majority of the patients had a malignant diagnosis or covid. The most common indication for phenobarbitone prescription was management of agitation at end of life not responding to high dose benzodiazepine/ anti-psychotics. All patients received stat dose of phenobarbitone 100mg followed by initiation of continuous subcutaneous infusion.
Conclusion: Phenobarbitone is a valuable and effective drug in management of terminal refractory agitation in selected cohort of patients.

Abstract number: B-66
Abstract type: Poster

Fostering Research in Swiss Nursing Homes

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Background: People living in nursing homes are most affected by frailty, multimorbidity and increasingly focused on palliative care research. Despite the stated need for improved care models, the experience of research participation is relatively new for swiss nursing homes (NH). In Switzerland, NH boards seem not to prioritize research. Contribution to large scale interventional studies in swiss NH remains relatively low. We nonetheless had to enrol 21 clusters with at least eight individuals for our SW-CRT beginning in the third quarter of 2020. To improve the recruitment process, we assessed the declines during recruitment which we present here.
Methods: First, We identified NH of decent sizes and locations from publicly available official nursing home listings. From June - October 2020, We contacted 209 NH Boards with short, easy to read written information on the study protocol. We individually documented each contact, and responses were archived for content analysis.
Results: Our request and reminder remained unanswered by 137 out of 209 (65%) NH.
Although the COVID-19 pandemic related public health regulations were still at their peak, COVID-19 was not the most prevalent reason stated in declines. Most boards declined while reporting concurring projects 18 out of 209 (8.5%), projects primarily involved new infrastructure. Twelve out of 209 (5.5%) of NH boards declined, stating lacking human resources for a research project.
Discussion: Only a third of NH invited to participate reacted to our request. 13.4% were interested or ready to join. Surprisingly only in four responses, NH stated the 2020 public health regulations as a reason for their decline. Compared to other literature, the boards never raised questions about confidentiality in their rejection.

Abstract number: B-67
Abstract type: Poster

Pharmacological and Non-pharmacological Treatment of Episodic Dyspnea in Advanced Lung Cancer Patients. A Nation-wide, Multicenter, Descriptive, Cross-sectional Study

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Background: Treatment of episodic dyspnea (ED) is largely variable. Pharmacological (PHT) and non-pharmacological (NPHT) treatments have been used.
Aims: To describe the PHT and NPHT of ED in a sample of advanced lung cancer (LC) out-patients treated in 10 Spanish hospitals aimed to estimate ED frequency in LC.

Methods: Consecutive advanced LC patients (Pts) visited in Palliative Care or Oncology clinics of 10 Spanish hospitals. A sample of 351 Pts would be needed to estimate ED frequency. Inclusion criteria:⩾18 y-old, stage III-IV LC & signed informed consent. Exclusion criteria: cognitive impairment, difficulty to understand & comorbidity acute exacerbation.
Results: We included 366 Pts. PHT was indicated in 79 Pts (67.5%); NPHT was used by 86 (84.6%) Pts. Fentanyl was the most used opioid (26 (54.2%)) and oral (buccal, sublingual, transmucosal) was the preferred route of administration (92.3%); morphine was used by 17 (35.4%) Pts. Anxiolytics were used by 24 (21.8%) of Pts. Most used NPHT were resting (92 (86.8%)); fisiotherapy (44 (41.5%)); oxygen (38 (33.6%)) and fan (30 (28.6%)).
Conclusion: Specific symptomatic PHT for ED in LC Pts was seldom used. Fentanyl was the most used opioid. Resting was the preferred NPHT. NPHT was more used than PHT and seemed to be faster in treating the episode.

Variable	**Pharmacological treatment in minutes (IQR 1-3)**	**Non-pharmacological treatment in minutes (IQR 1-3)**	**P value**
Time to onset of effect	5 (1-5)	2 (1-5)	**0.013**
Time to ED initial improvement	10 (1.5-20)	5 (2-10)	**0.075**
Time to ED complete relief	15 (3-30)	6.5 (2.25-10)	**0.107**

Variable	**All Sample (n; %) Complete cases = 366**	**Pts not reporting ED (n;%) Complete Cases = 249**	**Pts reporting ED (n;%) Complete Cases = 117**	**P value**
Opioids	154 (42.1)	95 (38.1)	59 (50.4)	**<0.001**
Inhaled bronchodilators	134 (36.6)	79 (31.7)	55 (47.1)	**0.007**
Oral steroids	105 (28.7)	58 (23.3)	47 (40.2)	**0.001**
Oxygen therapy	57 (15.6)	19 (7.6)	38 (32.5)	**<0.001**

Abstract number: B-68
Abstract type: Poster

Do Interventions for Malignant Pleural Effusions (MPE) Impact on Patient Reported Fatigue Levels & other Patient Reported Outcome Measures (PROMs)? A Prospective Pilot Study

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Background: Malignant pleural effusions (MPE) are common, affecting around 15% of people with cancer, an estimated 50,000 new cases per year in the UK. The presence of an MPE is a poor prognostic sign. It is therefore vital that we consider how we can support patients with MPEs to have the best quality of life possible. Previous studies have focused on how management of MPEs impacts on breathlessness but little is known about impact on other symptoms, particularly fatigue.
Aims: To assess if interventions for MPEs could potentially improve patient fatigue & symptoms reported through Patient Reported Outcome Measures (PROMs). This information will be invaluable for shared decision making on treatment for MPEs. This is a pilot study to gather data on whether a larger, multi-centre study is feasible.
Method: Patients attending pleural clinic to discuss potential interventions for their MPE were invited to take part. Written informed consent was obtained before completing FACIT-F score to assess fatigue and IPOS (Integrated Palliative Care Outcome Scale). Patients were then telephoned to repeat these scores at 7, 14 and 30-days post-procedure. Data was gathered on potential confounding factors.
Results: The average age of participants was 75 years, with lung cancer being the most common diagnosis. Initial results have shown that, after breathlessness, fatigue was the most common symptom reported. The initial trend appears to show some improvement in fatigue scores but further data collection is ongoing before statistical conclusions can be drawn.
Discussion: Patients experienced a high burden of fatigue and initial results are promising that management of MPE may help. This methodology was acceptable to participants and researchers and would be suitable for a multi-centre trial to gain larger numbers, since the attrition rate was high due to clinical deterioration or death, with only a third of patients being well enough to complete the scores at 30 days.

Abstract number: B-69
Abstract type: Poster

Evaluation of Nurse-led Administration of over the Counter Medicines in a Specialist Palliative Care Unit

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Background: In an inpatient setting, nurses can not administer medications unless they have been prescribed by a doctors. This includes medications that are available over the counter (OTC) in community pharmacies, some of which are essential to achieve effective and efficient symptom control. A Symptom Relief Medication (SRM) guideline was developed, whereby if "SRM" is prescribed in the as needed section of the drug kardex a nurse can administer any one of a list of OTC medications for symptom control.
Aims and objectives: This survey aimed to evaluate the effectiveness of the SRM guideline in a Specialist Palliative Care Inpatient Unit as perceived by the nurses.
Methods: A questionnaire assessing knowledge and opinions of the SRM guideline was distributed to all nursing staff by the Clinical Nurse Manager.
Results: 11 questionnaires were returned, response rate 44%. 100% of respondants answered correctly regarding principles of the SRM guideline and the medications it includes. 100% thought it was helpful overall, reduced patients' waiting time for symptom relief, and reduced doctors' workload. 63% thought that the SRM guideline reduced the

number of PRN medications on the prescription chart. Paracetamol was the most common medication given, followed by Gaviscon and saline nebulisers. 100% thought the SRM guideline contained the appropriate number of medications but a number of respondants gave free text feedback suggesting inclusion of additional medications.

Conclusions: Overall, nurses appear to be positive about the SRM guideline's workability and impact on patient care. An objective evaluation of prescription charts and patient feedback may be helpful.

Abstract number: B-70
Abstract type: Poster

Massage, Palliative Care, Speech and Language Therapy: which Pratices, which Benefits?

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Background: In recent literature, speech-language therapist (SLT) is increasingly recognized for its positive impact on the quality of life of people receiving palliative care (PC) (attenuation of communication and swallowing difficulties). Massage may be a tool: it helps patients to restore mobility to certain anatomical elements, stimulate communication... SLTs remain uncertain about their role in PC, calling for more research and specialized training.

Aims: Are palliative care and massage domains invested by SLTs today in France? Why is this? And if so, how? This study carries out an initial inventory of SLT massage practices in PC to improve patients' well-being by a more adapted monitoring and a better symptom management.

Method: An online survey was designed and piloted for this study, validated by an ethics committee, comprised of four sections: SLTs exercise general context, practices in PC, practices of massage, demographic information. A descriptive research methodology was chosen to describe the present existing conditions and behaviour without influencing them. Free text responses have been interpreted by inductive thematic analysis with an inter-judge validation, to identify and organize latent themes in an ascending approach, without influences. A review of the literature completed the results. 232 participations of SLTs working in France (metropolitan and overseas) have been collected.

Results: 59% of SLT provide PC still today and 63% massage. 47% are concerned with the practice of massage in PC and mentioned the strong benefits of massage in the therapeutic relationship, comfort, in functions maintain, tensions relaxation and muscular stimulation. A need for training on the subject was highlighted.

Conclusion: Benefits of SLT for patient in palliative care is evident and massage is such a tool for those benefices. This study may inspire practices for SLTs internationally and feed multidisciplinary reflection of other palliative care actors.

Abstract number: B-71
Abstract type: Poster

Role of Hemi-body Radiation In Prostate Cancer with Disseminated Bone Metastasis

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Background: Prostate cancer is the 2rd most common cancer in males, worldwide. Despite treatment many patients present with disseminated bone metastasis & even a few patients do present upfront. Radiation is an integral part of treatment for pain control & to prevent further bone related events. Ideally painful bone metastasis as well as weight bearing bones should be irradiated. Radionuclide therapy is the ideal treatment for disseminated bone disease, however the availability is limited & even not affordable for many patients.

Aim: To find out efficacy & toxicity of hemi-body radiation therapy in prostate cancer patients with disseminated bone metastasis.

Method: From Jan 2019 to Dec 2019 (12 months) at HCGCCK Cancer Centre, Nairobi, all prostate cancer patients with disseminated bone metastasis were selected for palliative hemi-body radiation therapy as Radionuclide therapy was not available in the country. Hemi-body radiation consists of 6 & 8 Gy dose, delivered to upper hemi-body & lower hemi-body respectively as single fractions, 1 week apart.

Pain relief (NRG-11 scale) & biochemical response (PSA level) were recorded at 6 weeks post radiation. Baseline evaluations for all patients were done at initial presentation. Complete blood count was ordered before & after radiation to access hematological toxicity.

Result: 15 patients were treated with hemi-body radiation. At the end of 6 weeks all 15 patients had variable pain relief & on Numeric Rating Scale-11, the average decline was 3 points. Average NRS scale rating was 7 before radiation treatment which declined to 4 after radiation. Mean PSA decline was 47%.

13 patients had grade I & 2 had grade II hematological toxicity. All recovered without any complication.

Conclusion: Hemi-body palliative radiation which costs 235 USD is a much cheaper alternative to Radionuclide therapy & offers good pain relief with acceptable toxicity.

Abstract number: B-72
Abstract type: Poster

Feasibility and Acceptability of Electronic Patient-reported Outcome Measures in an Outpatient Setting

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The new palliative care model 'Supportive and Palliative Care Review Kit in Locations Everywhere' (SPARKLE) comprises regular symptom monitoring using weekly online questionnaires, early identification and prompt response to identified problems and referral to palliative care services appropriately. This pilot study aims to determine the feasibility and acceptability of using electronic patient-reported outcomes (PROs) in an outpatient setting.

25 patients with Stage 4 lung cancer were recruited from the National Cancer Centre of Singapore (NCCS) outpatient clinic.

For 12 weeks, participants received a weekly link to the online Integrated Palliative Outcome Scale (IPOS) via text message. A nurse reviewed their responses and called them to assess the severity of their problems. If the problems were mild, patients were advised over the phone, if scored moderate to severe, patients were referred to existing palliative care models if needed.

Participants were also asked to complete a feedback survey online at the end of 12 weeks.

The rate of completion of the weekly IPOS declined over 12 weeks but was consistently above 50% except for one week when it was 47%. The percentage of patients with identified problems ranged from 50% to 82% over the 12 weeks. Apart from physical symptoms, other common problems reported were "Health", "Finance" and "Wellbeing".

Electronic PROs gives patients an avenue to report their problems and the assessment by the clinical team allowed for timely, tailored interventions. Of the patients who were assessed, 2 were referred to a palliative clinic, 2 to hospice home care, 1 to the chemotherapy review clinic. Generally, feedback by the patients on SPARKLE model of care was useful and they were satisfied and comfortable.

Abstract number: B-73
Abstract type: Poster

The Usefulness of Portable Ultrasound for Constipation in Palliative Care Setting

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Background: In the palliative care field, constipation is often associated with decreased activity and opioid medication. Portable ultrasound can be used not only by physicians but also by co-medical personnel because it is easy to carry and operate.
Aim: In this study, we will examine the usefulness of portable ultrasound for constipation in the palliative care field.
Methods: This is a prospective observational study of 134 hospitalized patients who were newly enrolled in the palliative care team of our hospital between April 2020 and December 2020 and whose consent was obtained for this study, in which using portable ultrasound, abdominal findings of the rectum and clinical symptoms were compared. We examined the presence or absence of structures with acoustic shading in the rectum, bowel movements and efforts, residual defecation, incidence of constipation according to Rome IV criteria, and stool properties using the Bristol stool form scale.
Result: The patients were 68 years old and 48% male. The primary sites were head and neck (22%), hepatobiliary (20%), and gastrointestinal (18%). 56% were under treatment and 44% were in best supportive care. Opioid use was observed in 556 patients. The prognosis was 62% monthly and 32% weekly; 66% had performance status 0-2 and 34% 3-4. 32% of patients had structures with acoustic shadows in the rectum. In the group with fecal masses in the rectum, compared to the group without fecal masses, background factors significantly included previous constipation, history of abdominal surgery, concomitant use of diuretics, Bristol stool form scale 1 and 2 as defecation status, and sensation of incomplete evacuation.
Conclusion: It was suggested that portable abdominal ultrasound is useful in diagnosing rectal constipation and confirming symptoms of dyspepsia in the palliative care field. In the future, diagnosis using portable ultrasound may become a support device for appropriate treatment selection.

Abstract number: B-75
Abstract type: Poster

The Knowledge and Use of Prognostic Scales by Oncologists and Palliative Care Specialists in Adult Patients with Advanced Cancer: A French National Survey (ONCOPRONO Study)

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Background: Prognostic scales exist to estimate patient survival in advanced cancer. There are no studies evaluating their use and practical utility.
Aim: To evaluate the proportion of respondents who had knowledge of these prognostic scales.
Methods: A descriptive national cross-sectional study was conducted between September 2019 and September 2020. An online questionnaire was prepared using international literature and sent to French oncologists and palliative care physicians.
Results: Participation rate was 9.6% (325 responses for 3 408 respondents), with 38% (175 responses for 454 respondents) for palliative care specialists and 4% (119 responses for 2 954 respondents) for oncologists. After sorting the respondents out of the inclusion criteria, 294 questionnaires were analysed. 63.6% (n= 187) had no or partial knowledge of prognostic scales. Palliative care specialists had better knowledge of those scales than oncologists (42.3% (n= 74) vs 27.8% (n= 33), $p = 0.015$). The Palliative Performance Status (PPS) and the Pronopall Scale were the best-known (respectively 51.4% (n= 55) and 65.4% (n= 70)) and the most widely used (35% (n=28) and 60% (n= 48)). Improving training on those scales was requested by 85.4% (n= 251) of participants. 72.8% (n= 214) did not use them. The lack of formation and consensus about the scale to use are the principal brakes for using.
Conclusion: This is the first national study on this topic. Due to the COVID-19 epidemic and a lack of research network between oncology and palliative care in France, the participation rate is a major limitation. To our respondents, there is a need for more information and teaching about prognostic scales in advanced cancer. So improvement concerning research network and teaching are requested. Furthermore, identifying circumstances in which prognostic scales should be used in real practice and clear international guidelines are needed.

Abstract number: B-76
Abstract type: Poster

Buprenorphine and Pain Treatment in Pediatric Patients: An Update

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Background: Pain is the most common symptom, a reason for medical attention during childhood and adolescence, despite knowing the magnitude of the harmful effects that pain can have on a child, is often inadequately evaluated and treated by ignorance and myths about the pathophysiological aspects of pain at this stage of life, and limited clinical information on the use of certain drugs. Opioids are an important therapeutic tool for treating moderate to severe persistent pain.
Problem statement: Buprenorphine, although not the first line of treatment in moderate to severe pain, has been shown to be an effective and safe analgesic with a prolonged effect in adult patients. Despite having nearly 40 years on the market, there is little information on its use, as well as its pharmacokinetic data in pediatric patients, especially in the treatment of chronic pain.
Objective: The purpose of this review is to provide an update on the clinical application of Buprenorphine (BFN) in the treatment of pain in children and adolescents.
Method: An intentional search was performed on studies of the use of buprenorphine in the pediatric or adolescent population focused on pain management, reported pharmacokinetic aspects, different

pharmaceutical forms and routes of administration, considering the clinical trials and reports available to date in the Biomedical databases.

Results: Studies on evidence of buprenorphine in children, although concluding with a strong recommendation for use in this population are rated as low quality and with poorly consistent results. Studies on the pharmacokinetics of BFN in children are scarce.

Conclusions: There is currently no clear evidence of the analgesic efficacy and safety of buprenorphine in the pediatric population. Pharmacological and biosafety studies are a priority to develop evidence-based regimens that allow safe use with a standardized dosage.

Keywords: Buprenorphine;Analgesia;Child;Adverse effects; Pharmacokinetics; Opioids; Pediatrics

Abstract number: B-78
Abstract type: Poster

Palliative Care for Patients with Itching – Issues Experiences by Healthcare Providers in the Netherlands: Results from an Online Survey

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Background: Of patients with cancer in the palliative phase, 10% experiences itching, which can have a major impact on the quality of life. Knowledge on treatment of itching has increased recent years. Therefore, the Dutch guideline 'Palliative care for patients with itching' is being revised. It is important to identify the current issues in order to align the guideline to the needs of healthcare providers.

Aims: Our aim was to identify issues experienced by healthcare providers experienced by Dutch healthcare providers and to prioritize these issues.

Methods: A multidisciplinary working group assigned for the revision of the guideline composed a 9 item survey based on their professional experience. An online survey was spread by working group members, relevant (professional) associations and social media. Respondents were asked to choose their 3 main issues. Results were analyzed using descriptive statistics.

Results: A total of 189 healthcare providers completed the survey. Respondents represented 14 professions, working in 8 different care settings and 57% treated 1 to 5 patients with itching in the palliative phase in the last year. 59% of respondents was palliative care specialist. The issues that were identified as most relevant were:

- Choice for systemic pharmacological treatment (51%)
- Diagnostics and determination of the cause of itching (43%)
- Choice for local pharmacological treatment (34%)
- Choice for non-pharmacological treatment (29%)

The most relevant issues differed between professions. The pharmacological treatment and diagnostics were the main issue for medical specialists, general practitioners and pharmacists (29-100%), whereas diagnostics and proper information were the main issues for (assistant) nurses (both 40%).

Conclusion: Healthcare providers identified the most relevant issues in the palliative care for patients with itching. These issues will be addressed in the revised guideline in order to optimize treatment for these patients.

Abstract number: B-83
Abstract type: Poster

Use of Medically Assisted Hydration at Home in Oncology Patients at the End-of-Life in Colombia

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Aim: To describe the characteristics of the patients who received medically assisted hydration at the end-of-life, its frequency of use, and duration of hydration in a palliative home care program in Colombia.

Methods: A retrospective, observational, cohort study of patients with cancer diagnosis enrolled in a palliative home care program in Bogotá, Colombia between June 1, 2017, and December 31, 2019. Patients older than 18 years of age with follow-up from admission to death were included. Patients with incomplete clinical records were excluded. A descriptive analysis of the continuous variables according to their distribution was carried out with Kolmogorov - Smirnov test, presenting measures of central tendency and dispersion, rate of use, type of hydration solutions, duration of use, and home care stay.

Results: Information from 323 electronic medical records that met the inclusion criteria were analyzed. The median age was 72 years (Q1-Q3: 61.2 - 82 years). In the age distribution, the highest proportion of patients were between 66 and 81 years old (41.5%). The use of medically assisted hydration in the study population was estimated at 87% (95% CI 0.825-0.899), with a distribution of saline use corresponding to 48% and 5% dextrose in saline solution to 49%. Administration route reported was intravenous 74.7% (n=209) and subcutaneous 25.3% (n=71). The median duration under hydration was 13 days (range 1-113 days) and the median at home care stay was 34.6 day (range 2-233 days). The three most common primary cancers were of colorectal (13.9%), lung (11.8%) and gastrointestinal (10.2%).

Conclusions: According with the results, the use of medically assisted hydration in patients with cancer at the end-of-life is a frequent intervention in our program. Results in literature are in keeping with our own. Assess side effects due to overload or excess hydration should be considered in future studies to adapt or adjust the use of this intervention.

C Posters Informal and Formal Caregivers

Abstract number: C-05
Abstract type: Poster

Factors Associated with Relatives' Evaluation on the Quality of End-of-Life Care in Nursing Home Residents with Dementia

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Background: Relatives provide a unique perspective on the quality of end-of-life care (EOLC) delivered to persons dying with dementia. Only a few studies evaluated the quality of EOLC from the perspective of relatives of nursing home residents with dementia, but no studies have investigated which sociodemographic, clinical and care characteristics are associated with the relatives' evaluation on the quality of EOLC.

Aim: To investigate which socio-demographic, clinical, and care characteristics are associated with relatives' evaluation of the quality of EOLC for a nursing home resident dying with dementia in Flanders, Belgium.

Methods: We combined data of two cross-sectional studies that were performed in 2010 and 2015. In total, 208 bereaved relatives were included (response rate: 54.6%). Quality of EOLC was measured with the

End-Of-Life with Dementia – Satisfaction With Care scale (EOLD-SWC (range 10-40)).

Results: When the deceased nursing home resident was a man, relatives evaluated the EOLD-SWC better than when the resident was a woman (b=1.792,CI: .221–3.362), $p < .05$). No association was found between the severity of dementia and EOLD-SWC (b=-1.524,CI-3.736-.87, p=.175). Relatives who received information on palliative care had a higher score on the EOLD-SWC compared to relatives who did not receive this information (b=3.926,CI: 2.345–5.506, $p < .01$). Relatives who received information on medical care from a care provider evaluated the EOLD-SWC better than relatives who did not (b=3.603,CI 2.072–5.133, $p < .01$).

Conclusion: This study shows that informing relatives about nursing home residents' medical care and palliative care improves relatives' evaluation on the quality of EOLC. Involving relatives as a member of care team would facilitate the information-transfer about the (end-of-life) care of the resident.

Abstract number: C-09
Abstract type: Poster

The Experiences of Fathers of Children with A Life-limiting Condition: A Systematic Review and Thematic Synthesis

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Background: Children with a life-limiting condition often require extensive and complex care, much of which is provided by their parents at home. Palliative care forms an essential part of the care that many of these children receive, often from the point of diagnosis. There is a growing body of research that aims to understand the experiences of their parents, but the majority of this research is from mothers' perspectives, meaning that fathers' experiences are not well understood.

Aims: To identify and synthesise findings from existing qualitative studies that have explored the experiences and of fathers of children with a life-limiting condition.

Methods: A systematic review of qualitative research was conducted using thematic synthesis. Searches were conducted in MEDLINE, CINAHL, EMBASE, PsycINFO and Social Science Citation Index.

Results: Findings from 30 studies were included, representing the experiences of 576 fathers of children with a range of diagnoses including cancer, cystic fibrosis, genetic and neurological conditions. Themes detailed fathers' experiences of uncertainty and shock around the time of their child's diagnosis, their accounts of a 'new normal', difficulties in discussing their emotions, forming relationships with and seeking support from professionals, and working fathers' role conflicts. They discussed the life-changing nature of their child's diagnosis, an event that affected all aspects of their lives from everyday activities, to their relationships, spirituality, values and ambitions.

Conclusions: Fathers experience many difficulties in response to their child's diagnosis and ongoing treatment. Findings highlight the need for healthcare professionals to recognise individual family dynamics and the evolving role of the father. Fathers' responses are not widely understood, and research that directly addresses their own wellbeing is warranted in order to provide them with appropriate support.

Funding: NIHR

Abstract number: C-10
Abstract type: Poster

How Do Family Caregivers of Persons with a Serious Chronic Illness Collaborate with Healthcare Professionals for their Caregiving Tasks? A Cross-sectional Survey of Bereaved Family Caregivers

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Background: Previous research has described family caregivers' tasks *(providers of care)* and care needs (*care clients*). Little evidence is available about how they are supported by healthcare professionals, e.g. through education and empowerment, in providing care (*members of the care team*).

Aim: To investigate how family caregivers of persons with serious chronic illness collaborate with and receive support from healthcare professionals for family caregiving in the last 3 months of life.

Methods: Population-based cross-sectional survey of bereaved family caregivers of persons with a serious chronic illness (N=3000), identified through the three largest sickness funds in Flanders, Belgium (79% of the population), who cared for a person who died 2 to 6 months before the sample was drawn (November '19). The survey asked about collaboration with healthcare professionals for various caregiving tasks in 3 months before bereavement. Multivariable logistic regression was performed to control for confounding when examining factors associated with collaboration.

Results: Response rate was 53.3%. Most family caregivers received support from one or more healthcare professionals for family caregiving tasks they performed, ranging from 71.4% for promoting social interaction to 95.3% for managing symptoms. This support was from a palliative care nurse or doctor in 7.6% (facilitate safe movement) to 36.6% (help talk about end of life). The type of support of healthcare professionals mostly concerned informing family caregivers rather than involving them. Use of palliative care services was the strongest predictor of collaboration with family caregivers across physical, psychosocial and practical caregiving tasks.

Conclusion: Most family caregivers of persons with serious illness get some form of support from healthcare professionals for their family caregiving tasks. However, a more empowering support strategy for family caregivers, e.g. aimed at increasing self-efficacy, is rare.

Abstract number: C-11
Abstract type: Poster

Caring, Bereavement & Bureaucracy: A Qualitative Study of Australian Social Welfare Policy and Caring in the Context of Life-limiting Illness

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Background: Caring and bereavement in the context of life-limiting illness are associated with cascading challenges that may contribute to social welfare needs related to income and housing. Yet potential for carer experiences to be shaped by social and structural inequities is underexplored, including consequences of interactions with public institutions and social policy.

Aims: To explore the experiences of former carers of people with life-limiting illnesses and social welfare needs in a developed region of recognised socioeconomic disadvantage.

Methods: Underpinned by an interpretive descriptive approach, in-depth interviews were undertaken with specialist palliative care workers (n=7), welfare sector workers (n=14) and bereaved former carers of people with life-limiting illnesses (n=12). Data were analysed using framework analysis.

Results: Participants described relevant welfare policy and process related burdens that may contribute to financial, housing and employment precariousness and structural vulnerability during and post-caring. Personal, interpersonal and structural factors that affect the navigation of income support and housing needs were articulated, alongside recommendations that may improve carer experience.

Conclusion/ discussion: The intersection of certain social locations and structural determinants such as inequitable policy, complex application processes, increasingly virtualised support, lacking grief literacy of workers and transactional agency cultures appears to shape the capacity of carers to navigate welfare issues, with potential to undermine individual agency, heighten structural burden and increase precariousness. Findings point to needed advocacy in liberal welfare states for welfare policy and processes that are more responsive to end-of-life caring and bereavement, and increased recognition of the potential for systemic disenfranchisement of vulnerably positioned carers.

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Abstract number: C-12
Abstract type: Poster

"Caregiver Activation" of Relatives of Patients with Advanced Cancer and its Association with Caregiver Burden and Wellbeing

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Background: Relatives of patients with advanced cancer often have to deal with many caring responsibilities, regardless of their knowledge, skills and confidence to provide this care (also known as 'caregiver activation'). These aspects of caregiver activation are hypothesized to be associated with their caregiver burden and well-being.

Aim: To assess caregiver activation in relatives of patients with advanced cancer and its association with sociodemographic and psychosocial characteristics.

Methods: We conducted a cross-sectional study on caregiver activation among 300 relatives of patients with advanced cancer. The study was nested in a nationwide prospective longitudinal observational cohort study (eQuipe study). We assessed caregiver activation by the Caregiver Patient Activation Measure (C-PAM; range 0 – 100). We also assessed resilience, caregiver burden, personal self-care, depressive symptoms, quality of life, social well-being and relatives' sociodemographic characteristics. Univariate regression analyses were performed.

Results: Relatives had a mean C-PAM score of 54 (SD 13). Higher caregiver activation scores were found among partners (compared to other family members) ($p = 0.01$), males ($p = 0.02$), those who provided informal care in the last three months ($p = 0.01$) and those being more resilient ($p < 0.01$). Moreover, those with higher activation scores had significantly lower caregiver burden scores ($p = 0.03$) and higher scores on personal self-care ($p = 0.03$) and social well-being ($p = 0.01$).

Conclusion: There is quite some variation in levels of caregiver activation, which can be partly related to relatives' personal characteristics and one's role in the care process. Higher caregiver activation seems to be associated with less burden and a better wellbeing of relatives. Empowering relatives of patients with advanced cancer in managing the care for their loved one may improve their own well-being.

Funding: Dutch Research Council (NWO, VIDI)

Abstract number: C-13
Abstract type: Poster

The Required Competencies of Licensed Practical Nurses within Palliative Care from the Perspectives of Multi-professional Expert Groups: A Qualitative Study

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Background: Licensed practical nurses (LPNs) often participate in the care of palliative and end-of-life care patients. Thus, they need to have good competencies in palliative care.

Aim: To describe the competencies required from LPNs working within palliative care from the perspectives of multi-professional groups of representatives from working life.

Methods: The data of this qualitative descriptive study ($n = 222$) was collected in workshops held in different parts of Finland, wherein the participating professionals and representatives of patient organizations discussed the competencies that are required in palliative care, before reaching and documenting a consensus. The data was analyzed using a content analysis method.

Results: The description of the competencies required from LPNs within palliative care included 15 main categories and 59 subcategories in total. 'Competence in rehabilitative holistic nursing and caring' was the main category which was obtained from the highest number of reduced expressions from the original data. 'Competence in encountering and social interactions' was another strong main category. The third large main category was 'Competence in holistic consideration and support of the patient and the closest ones'. The other main categories were related to competencies in cooperation, symptom management, starting to act and breaking the bad news, reporting, pharmacological treatment, patient-focused practice, assessment of the patient's condition, pain management, development of oneself and one's own profession, as well as understanding of the content of palliative care, palliative care pathway, withholding of therapies and goals of care, and understanding death and nursing care associated with it.

Conclusions: The results especially emphasize holisticness, rehabilitation, encountering and social interactions in LPNs work within palliative care. The diversity of the categories reflects the richness of the work of LPNs in palliative care.

Funding: This research was supported by The Developing Palliative Nursing and Medical Education through Multidisciplinary Cooperation and Working-life Collaboration project, which was funded by the Ministry of Education and Culture in Finland (Decision 29.3.2018 OKM/258/523/2017) and the participating higher education institutions.

Abstract number: C-14
Abstract type: Poster

Narratives of the End-of-Life Family Caregiving Experience at Home

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Background: Occurring at home, the process of dying is becoming a part of family life again. But the responsibility of care falls largely on the family, a situation which challenges the stability and well-being of all the members. However, there is a significant gap in knowledge concerning this phenomenon since most research has focused on the caregiving impact on the main carer. This gap highlights the need for more in-depth knowledge about families' experiences providing end-of-life care.
Aims: To understand the experiences of families during the care of a terminally-ill relative at home.
Methods: In primary health care, a narrative research study was conducted to address this phenomenon. Nine families were interviewed as a group, and 23 members of these families were interviewed individually. The interviews were transcribed and analysed using thematic narrative analysis.
Results: The families experiences were classified into six themes: 1) normalisation of a new life centered on the ill relative, 2) the need for all the family members living in the home to care for the ill member, 3) the feeling of satisfaction in fulfilling the moral duty of caring for their ill relative, 4) ambivalence regarding their ill relative's imminent death, 5) the disruption of family well-being and 6) lack of attention from the social and health services.
Discussion: This research highlights the impact of care-provision on the health of families as a whole. Families feel neglected, abandoned to their own fate during the final phase of their loved ones' lives and demand to be supported. Their immediate social environment and their reference health-care professionals are turning their backs on them. It is imperative, therefore, to change the paradigm in society as a whole, and in the social and health care services, regarding family end-of-life caregiving. All efforts to provide help will be in vain unless accompanied by the holistic support of the social health services.

Abstract number: C-15
Abstract type: Poster

Health-related Quality of Life and Emotional Well-being Connected to Glioblastoma; A Longitudinal Follow-up Study Involving the Patients' Relatives

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Background: Glioblastoma is the most common primary malignant brain tumor, it is incurable and has a poor prognosis. Glioblastoma can cause a rapid decline in patients' cognitive and physical abilities, and this can be an important cause of distress for relatives.
Aim: Investigate the health-related quality of life (HRQoL) and emotional well-being among relatives to patients with glioblastoma from a longitudinal perspective.
Methods: Preoperative, at 3 weeks, 12 weeks, 6 months and 1 year, and at 1.5 years postoperative between 2012 and 2018, the relatives evaluated their HRQoL by answering the Short Form Health Survey (SF-36) and their emotional well-being by using the Hospital Anxiety and Depression scale (HADS). At baseline the population consisted of 63 relatives. Descriptive statistics were used and the Friedman test evaluated any changes over time.
Results: The relatives had the lowest mean score for all the mental components in SF-36; mental component summary (MCS) 22.6, vitality (VT) 38.9, social functioning (SF) 47.9, role emotional (RE) 23.0 and mental health (MH) 44.5 at 3 weeks postoperative. Further, the relatives had a significant change over time from preoperative and until 6 months postoperative in most of the mental components in SF-36 MCS $p=0.003$, VT $p=0.005$, SF $p=0.03$ and RE $p=0.05$. 83 % of the relatives estimated symptoms of anxiety at 3 weeks and 90 % at 1.5 years postoperative. The relatives' distress level remained high and significantly unchanged over time from preoperative and until 6 months postoperative.
Discussion: The relatives' HRQoL and emotional well-being were negatively affected early on in the illness trajectory and remained affected over time. Palliative care should be considered in the early stages of the disease, perhaps already at the time of diagnosis to support both patients and their relatives.

Abstract number: C-17
Abstract type: Poster

Family Caregivers' Crises in the Palliative Home Care Setting: How Do Hospice and Palliative Care Staff Support Families?

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Background: Family caregivers (FCs) of terminally ill patients experience psychosocial/physical burdens and manage complex responsibilities. The occurrence of FCs' crises in palliative home care is likely, but little is known about the effects on FCs and how they are supported.
Aims: To gain a better understanding of FCs experiencing crises in palliative home care from the perspective of hospice and palliative care staff.
Methods: Qualitative study with an interpretative description approach. Ten multi-institutional focus groups were conducted with interdisciplinary teams from palliative care and hospice services (n=64). Verbatim transcripts were analyzed according to the grounded theory methodology using Strauss' coding paradigm.
Results: FCs are highly affected by crises, in their roles as both caregivers and persons in need of support, and multiple causes were identified. Staff's strategies to avoid FCs crises include monitoring of potentially stressful situations and FCs' burden, psycho-education, and communication. When crises occur, strategies include intensified practical/emotional support for FCs, suggesting coping strategies, and helping FCs to accept their role as a person in need of support. However, strategies are challenged by limited resources of the attending staff, FCs' unwillingness to use available forms of support, and FCs' commitment to promises for a home death. Successful support can result in the alleviation of FC's physical/mental strain, review of self-care needs, and ultimately maintenance of home care. The admission to a palliative care unit was evaluated as ambivalent regarding beneficial (i.e., recovery period) and distressing consequences (i.e., feelings of guilt) for FCs.
Discussion: Our results form the basis of a relational model regarding FCs' crises in palliative home care. They may contribute to the development of recommendations and staff trainings focusing on the prevention and navigation of FCs' crises and FC support.

Abstract number: C-18
Abstract type: Poster

Is there any Relationship between Sleep Disturbance of Greek Family Carers of Advanced Cancer Patients with the Caregiving Burden and Outcomes? A pilot study

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Background: Sleep disturbance are a common issue for those who provide informal care to someone with a life-limiting condition.
Aim: Explore the sleep disturbances among family carers of patients with advanced cancer.
Methods: The convenient sample, of this descriptive, cross-sectional study, consisted of 100 family carers (response rate 92%) of hospitalized advanced cancer patients' in a cancer hospital (May 2019-September 2019). Inclusion criteria: adult family carer's named by hospitalized advanced cancer patients, consent to participate. The following validated in Greek language measurement tools were used: a) the Greek Pittsburgh Sleep Quality Index (PSQI), b) Bakas Caregiving Outcomes Scale (BCOS) and the translated into Greek c) Oberst Caregiving Burden Scale (OCBS), The statistical significance level was set at 0.05.
Results: Most of the participants were females (72%) and the sample's mean age was 57,51±13,17 years old. Most carers were married/or partnered (78%) and were partner or child of the patients (34%). The mean duration of care provision was 16,3 months, and the mean patients' ECOG performance status score was 3. Family carers experienced moderate overall sleep difficulty (10,11±4,26) and were significantly burdened by caregiving in terms of time (47.74±10.55) and mildly burdened by caregiving in terms of difficulty (40.89±11.92) (OCBS). Participants reported moderate mean overall positive caregiving outcomes (48,49±12,76) (BCOS). Multivariate analysis showed that family carers who needed more time for care provision, those with basic education and women occupied only with household, had more sleep difficulties ($R^2 = 0,185$, F=3.14, p=.003 (f2=.267)).
Conclusions: Family carers of advanced cancer patients experience moderate overall sleep difficulties. The relationship of Caregivers' burden, life changes as a result of caregiving and sleep disturbances must be further explored.

Abstract number: C-20
Abstract type: Poster

A Narrative Exploration of the Experiences of Informal Caregivers for People with Moderate to Advanced Dementia within a Domestic Home Setting towards the End of Life

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Background: Knowledge of the experience of unpaid caregivers for people with moderate to advanced dementia within a domestic home setting, especially towards the end of life is limited. Their experience is usually described in terms of internal conflicts and powerlessness in making changes to their situation. Similar experiences have been reported by nurses and other healthcare professionals. These accounts have been described as moral distress, but the experiences of the unpaid home-based caregivers are yet to be investigated.
Aim: The aim of this study was to answer the question: "What are the narratives of care provision by informal caregivers, and how do they describe their experience of home-based care for people with moderate to advanced dementia towards the end of life?"
Design / Methods: A narrative inquiry design was adopted in collecting data using unstructured interviews. 15 people in the UK were recruited as participants if they were either providing unpaid care at home for someone with dementia within the moderate to advanced stages at the time of the interview or did so within the previous 6 months. A textual narrative approach by Riessman (2008) was adopted in analysing collected data.
Results: Narratives were presented under five headings of loss, control, role change, coping and help-seeking, with evidence showing characteristic plasticity of experience of moral distress as possibly moulded by the internalised conflicts encountered in caregiving.
Discussions / Conclusions: Participants' experiences described a role transformation following a dementia diagnosis. A reduction of the unsuitability of support received within the moderate to the advanced stages necessitates a policy on decline-specific post-diagnosis support for unpaid home-based caregivers. Further research is also necessary to explore whether increased internal conflicts lead to an increment in caregivers' moral distress.

Abstract number: C-21
Abstract type: Poster

Palliative Care Healthcare Professionals' Work-related Stress: A National Cross-sectional Survey

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Background: Providing palliative care can lead to work-related stress and ultimately to burnout. The need for palliative care will further increase due to population aging and people living longer with life-threatening diseases. Therefore, a healthy palliative care workforce is vital.
Aims: This study aims to get insight into the experienced work-related stress among health care professionals providing palliative care in the Netherlands and their strategies and needs in relation to maintaining a healthy work-life balance.
Methods: A cross-sectional online survey of members of the Dutch Association for Palliative Care Professionals was conducted between February and March 2020. Burnout was assessed by the validated Burnout Assessment Tool (BAT). Self-constructed questions assessed the used strategies and needs of health care professionals providing palliative care regarding work-related stress. Descriptive analysis were performed using STATA.
Results: In total 179 eligible respondents completed the questionnaire (response rate 54%). Most were female (79%) and older than 50 years (66%). Nurse (47%) and physician (39%) were the most prevalent profession. Two-thirds (69%) experienced a medium level of burnout and 2% reported a high level. Furthermore, 7% had ever been on sick leave due to burnout. Health care professionals engaged in numerous coping activities (mean 3.7), but a quarter (23%) of all respondents felt that these activities were not sufficient to maintain balanced. Respondents felt a need for activities aimed at the team or organisation level such as feeling emotionally safe within their team.
Discussion: Symptoms of burnout are quite prevalent among health care professionals providing palliative care in the Netherlands. Health care professionals express a need for team and organisation approaches in addition to their individual coping strategies to maintain a healthy work-life balance.

Abstract number: C-22
Abstract type: Poster

To Participate in a Randomised Double-blind, Placebo-controlled Study at the End of Life: Experiences of Relatives

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Background: Placebo-controlled trials may provide evidence to support end-of-life care, but it is contested whether asking dying patients to participate in such trials is morally justifiable.

Aim: To better understand the experience of participating in a placebo-controlled trial at the end of life from the perspective of relatives.

Methods: The SILENCE study is a randomised, double-blind, placebo-controlled trial on the efficacy of scopolamine butylbromide (SB) to prevent death rattle. Patients gave advance written informed consent after admission to the hospice. Bereaved relatives were invited to fill in a questionnaire three months after the death of the participant and to participate in an interview.

Results: Of 154 invited relatives, 104 completed the questionnaire and 17 were interviewed. Ten percent of the relatives thought that the participation of their loved one in research was a bit burdensome for their loved one and 14% it a bit stressful or burdensome for themselves or for other relatives. Eighty-three percent considered participation in research in general as (very) valuable. The in-depth interviews showed that patients' decision to participate in this study was made in close consultation with relatives. Consultation consisted of asking relatives what they thought of the research and the invitation to participate. Relatives had respect for and felt mostly proud about patients' decision to participate.

Conclusion: Participation in a placebo-controlled trial at the end of life was decided by the patients in close communication with their relatives. These relatives mostly evaluated participation as a positive experience. This study indicates that participation in a placebo-controlled trial at the end of life is acceptable from the point of view of bereaved relatives and, by using an advance consent procedure, morally justifiable.

Abstract number: C-23
Abstract type: Poster

Supportive Interventions for Family Caregivers of Patients with Advanced Cancer: A Systematic Review

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Background: Family caregivers are often intensively involved in end-of-life cancer care and therefore have a unique position of both providing and needing support. Little is known about which (components of) supportive interventions in this context are effective. We performed a literature review to provide a systematic overview of interventions to support family caregivers of patients with advanced cancer and their effectiveness.

Methods: Embase, Medline Ovid, Web of Science, Cochrane Central, Google Scholar and Cinahl were systematically searched. We included quantitative studies published from January 2004 until December 2019 reporting about interventions to support adult family caregivers of patients with advanced cancer. Data were extracted on target group, delivery format, intervention components and outcomes. Methodological quality was assessed with the Quality Assessment Tool.

Results: Out of 7954 titles and abstracts, 32 articles were included. Nineteen studies concerned randomised controlled trials. The supportive interventions were delivered in different settings to four types of target groups: individual family caregivers (n=12), dyads (n=11), families (n=2) and larger groups (n=7). Two interventions were delivered online, 29 interventions face-to-face or by phone, and there was one self-administered intervention. The number of intervention sessions ranged from one to ten. Most interventions included multiple components, often based on family caregivers' needs. Outcome measures used were highly variable.

Conclusion: We found a variety of interventions to support family caregivers in palliative cancer care. Most interventions consisted of multiple components and focused on family caregivers in relation to other relatives or peers. The effects of these interventions have been studied in various settings and target groups using different outcome measures.

Abstract number: C-24
Abstract type: Poster

The Role of Gender in Compassionate Care: Gender Differences Are Not only Mean Differences

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Background: The relation between gender and compassionate care has been investigated, with different results. Some studies have found gender differences in compassion satisfaction, others had pointed higher levels of compassion fatigue in women, and some have not found differences at all.

Aims: To study the relation between gender and compassionate care, deepening in the impact of gender on the relations among variables.

Methods:

Design: The research has a panel design. Palliative care professionals participate during years 2020-2022. Data of the first wave were used.

Data collection: 296 professionals participated. 229 were women.

Analysis: Statistical analyses included t tests for means and z tests for correlations.

Results: Mean differences between genders were not found for self-care, awareness, compassion, or professional quality of life.

However, the relations among these variables did show gender differences. As regards the predictors of compassion in palliative care professionals, physical self-care (z=2.525;p<.001), social self-care (z=2.026;p=.021) and awareness (z=2.176;p=.015) were higher protectors for men, with statistically significant differences among correlations. In this same line, compassion had a higher predictive power on compassion satisfaction (z=2.285;p=.011) and was a stronger protector of burnout (z=-1.656;p=.049) in men.

Conclusion: Gender has proved to have an important role when studying compassionate care. Although men and women have shown the same levels of self-care, awareness, compassion, and quality of life; gender differences have been found in the relations among variables. Men benefit the most from the increase of self-care and awareness in terms of an increase of compassion; showed a closer relation between compassion and compassion satisfaction; and also compassion had a greater protective effect against burnout for them.

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Abstract number: C-25
Abstract type: Poster

Sources of Stress for Palliative Care Professionals: The Role of Conflict and Lack of Colleagues' Support

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Background: The importance of receiving ongoing support within teams and organizational cultures for palliative care professionals has been pointed. Support from colleagues can contribute to wellbeing and resilience, and its absence can lead to burnout.

Aims: To describe levels of stress derived by conflict and social support in Spanish palliative care professionals and their relationships.

Methods:

Design: The research has a panel design, in which palliative care professionals will participate during years 2020-2022. Data collected in the first wave are used.

Data collection: 296 professionals of palliative care participated.

Analysis: Statistical analyses will include descriptive information and inferential analyses for the relations among the variables under study.

Results: 31% of the respondents frequently suffered stressful situations derived from conflicts with other professionals, and 3.7% almost always; 30.6% of the frequently suffered stressful situations derived from lack of support, and 5.1% almost always.

No differences in stressful situations derived from conflicts with other professionals or from lack of support were found between men and women. When nurses and physicians were compared, again no differences were found.

Regarding the relation with professional quality of life, stressful situations derived from both conflicts with other professionals or lack of support were not related to compassion satisfaction, but predicted burnout and compassion fatigue.

Conclusion: Stressful situations in palliative care professionals derived from problems with colleagues are more common than desirable. Furthermore, they do not distinguish between gender or profession. It is essential to work on the support of colleagues and the proper functioning of work teams, since these variables can lead to greater burnout and compassion fatigue.

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D Posters Older People

Abstract number: D-04
Abstract type: Poster

Willingness to Engage in Advance Care Planning among Older Workers who Work in the Community: Single-centered Cross-sectional Study

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Background: The yearly number of older workers has consecutively increased in Japan. The Japanese Silver Human Resources Center (SHRC) is a public-service organization. SHRC coordinates paid jobs to people aged over 60 years with a sense of well–being through work and contributes to the vitalization of local communities. The majority of SHRC members work to maintain their health. However, older people who work are at risk of becoming severely sick at any time because of their age.

Aims: The primary aim of this study was to assess the current situation of willingness to engage in advance care planning (ACP) among older workers who work within their community.

Methods: We conducted a single-centered cross-sectional study at SHRC.

Results: We mailed the questionnaires to all SHRC members (n = 721). The median age of the participants was 74 years, ranging from 60 to 89 (IQR 70–78). Of the 327 participants, 208 (63.6 %) reported that they planned to write end-of-life wishes. Of the 208 participants, nearly 80% are planning to document ACP because they do not want to bother their family. Of the 327 participants, 113 (34.5%) reported that they were not planning to document ACP. Of the 113 participants, 30% considered that the wish of their family regarding their end-of-life is much more important than their own preference.

Conclusion: The majority of participants who agreed to document ACP reported that they do not want to bother their family. In Japanese culture, causing trouble to others is called meiwaku that should preferably be avoided. The most common reason why participants did not agree with ACP documentation was that the wishes of the family and other people around the individual were more important than their own. Compared to Western countries, where autonomy is valued, the Japanese culture values harmony, which is called wa. Our study results are useful to understand the preference of ACP in the Japanese culture among older workers.

Abstract number: D-07
Abstract type: Poster

The Prevalence of Chronic Breathlessness and Associated Psychological Symptoms in a Frail, Elderly Population within a Community Setting: A Cross-sectional Survey

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Background: The UK has an ageing population and frailty is often a consequence, with a prevalence of 10% in those over 65. Chronic breathlessness is often debilitating, affecting approximately 1/3 of older adults and is associated with psychological distress. We have limited understanding about the impact of chronic breathlessness on older, frail people in the community setting.

Aim: To determine the prevalence of chronic breathlessness and to identify associated psychological concerns in older, frail people in the community.

Methods: An observational, cross-sectional survey was conducted as part of a service evaluation of a new Integrated Care Clinic for frail older adults. Participants ⩾65 at risk of severe frailty were recruited at their multi-disciplinary pro-active assessment. The survey included: Integrated Palliative care Outcome Scale (IPOS), EuroQol-5D (EQ-5D-5L) and a bespoke screening question for chronic breathlessness "Have you suffered with breathlessness for most days in the last month?". Descriptive statistics reported clinical characteristics for those with and without chronic breathlessness. Associations between chronic breathlessness and psychological concerns were explored (Odds Ratios [OR]).

Results: 99/249 (39.8%) survey respondents (median age 80, 61% women) self-reported chronic breathlessness; they had increased odds of having anxiety (IPOS) (OR 2.2; 95%CI 1.29–3.85), family anxiety (IPOS) (OR 2.0; 95%CI 1.20–3.41), and depression (IPOS) (OR 1.9; 95%CI 1.12–3.39) compared to those without chronic breathlessness. Findings did not change after adjustment for age or sex.

Conclusions: Chronic breathlessness is common in older, frail adults. These individuals had increased odds of psychological concerns such as anxiety (personal and family) or depression. Chronic breathlessness should be actively identified and managed within primary care to avoid adverse psychological consequences and deliver targeted interventions.

Abstract number: D-08
Abstract type: Poster

A Retrospective Cohort Study to Compare Survival Days, Place of Death and Medical Utilization between those Receiving Hospital-based Palliative Home Care and Community-based Palliative Home Care

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Background: Evidence shows that community-based palliative home care (PHC) provision could enhance the continuous care through the patient's illness trajectory from hospital-based care back home, and improve patient outcomes. However, there is little evidence regarding community-based palliative home care based on Taiwanese context.

Aim: To compare community-based PHC with hospital-based PHC in terms of the patients' survival, their place of death and medical utilization in Southern Taiwan.

Method: A retrospective cohort study using chart review from May 2018 to December 2018. Adult patient aged $>$18 years old diagnosed with any disease who receiving either hospital-based or community-based service were recruited. Descriptive analysis, Chi-square test, t-test and Log-rank test were conducted.

Results: One hundred and thirty-seven patients with averaged 75 y/o (SD± 12.33) were recruited for hospital-based services and 46 with averaged 72 y/o (SD± 12.57) for community-based services. The majority were married (51%) female (55%) with education less than 6 years (55%). More than 90% of patients were diagnosed with cancer with ECOG score 3 (49%) and 4 (49%). Majority of participants in hospital-based group (44%) died at hospice wards, but people in community-based group died at home (51%). Distance from patients' home to the hospital significantly influence their decisions for community-based services ($p<.001$). Patients in hospital-based group received more physician visits ($p = .03$) and total caring days before death ($p = .001$). However, more nurse visits were found in community group ($p = .008$). There is no difference on the patient's survival days ($p = .63$) and place of death decisions ($p = .20$) between two groups.

Conclusion: Community-based palliative care should be promoted to enlarge universal health coverage for ageing societies such as Taiwan, although community-based palliative care equips less staffing and resources compared to hospital-based services.

Abstract number: D-10
Abstract type: Poster

Attitudes to Aging and Dignity in Czech Community-dwelling Older Adults and Geriatric Inpatients

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Background: Attitudes to aging are social constructs that are culturally and historically determined, as well as individually interpreted. Personal dignity is a multidimensional construct that includes perception, knowledge, and emotions related to competence or respect.

Aims: To examine how community-dwelling older adults and geriatric inpatients evaluate attitudes to aging, and whether dignity affects their attitudes to aging.

Methods: Cross-sectional study with two questionnaires (Attitude to Aging Questionnaire [AAQ], and Patient Dignity Inventory [PDI-CZ]). 233 geriatric inpatients ($M_{age} = 80.7 \pm 7.0$ years) and 237 community-dwelling older adults ($M_{age} = 74.9 \pm 6.4$ years) from two regions of the Czech Republic were enrolled in the study. Independent samples t-tests, Spearman correlation analyse and multivariable linear regression were used for statistical processing.

Results: The geriatric inpatients had more negative attitudes to aging (total AAQ score [$M = 74.9 \pm 10.9$; $p < 0.0001$]; Psychosocial Loss [$M = 24.5 \pm 5.6$; $p < 0.0001$] and Physical Change domains [$M = 23.1 \pm 5.1$; $p = 0.008$]). The attitudes to aging affecting factors in geriatric inpatients were gender and dignity. Women (ß = -2.969, $p = 0.045$) and inpatients with poor dignity ratings (ß = -0.332, $p < 0.0001$) had more negative attitudes to aging. The attitudes to aging affecting factors for community-dwelling older adults were education, living arrangement, and dignity. More negative attitude to aging were experienced by older adults with lower education (ß = 2.716, $p = 0.007$), living alone (ß =2.163, $p = 0.046$), and rated their dignity as low (ß = -0.325, $p < 0.0001$).

Conclusion/discussion: Our results suggest that dignity values evaluated using the PDI-CZ questionnaire, are among the factors affecting attitudes to aging in both community-dwelling older adults and geriatric inpatients.

Supported: by the Ministry of Health of the Czech Republic (grant nr. NU20-07-00100).

Abstract number: D-12
Abstract type: Poster

Prevalence and Patterns of Opioids Currently Prescribed in Community-dwelling Older Adults Living with Frailty

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Background: Opioids are used to manage moderate to severe pain. Older adults ($\geqslant$65) with frailty may be more at risk of adverse effects, but we have limited data to inform our understanding.

Aim: To determine the prevalence and patterns of opioids prescribed to community-dwelling older adults living with frailty.

Methods: Opioid prescription data were extracted from medical records for this group. 'Current' opioid use was defined as having an opioid prescription within 30 days of recruitment. Prescriptions were grouped into regularly scheduled or *pro re nata* (PRN). Opioid dose was converted to oral morphine equivalent (OME) and presented in milligrams per day. The lowest and highest possible doses are provided where a range in dose was present. Descriptive statistics are presented.

Results: 80/247 (32.4%) participants were currently prescribed an opioid. 43/80 (53.8%) had regularly scheduled opioids prescribed; 30 (37.5%) had PRN and 7 (8.8%) had both. Codeine was most commonly prescribed (n= 40, 50.0%), followed by tramadol (n= 15, 18.8%), transdermal buprenorphine (n= 10, 12.5%), and morphine (n=10, 12.5%). Less commonly prescribed opioids included dihydrocodeine, fentanyl, meptazinol and oxycodone. The lowest median OME dose for codeine was 9mg (IQR 3.2, 12.0); the highest OME dose was 12mg (IQR 6.4, 24.0). Median OME doses also varied for tramadol (20mg (IQR 20.0, 40.0) to 40mg (IQR 20.0, 40.0)) and morphine (40mg (IQR 20.0, 105.0) to 50mg (IQR 20.0, 105.0)). Median OME dose for buprenorphine was 24mg (IQR 12.0, 45.0).

Conclusion: Opioids were prescribed to a third of older adults living with frailty. Codeine and tramadol were most commonly prescribed, despite having a limited role in this population due to adverse effects and variability in effect. Careful selection of opioids is warranted; further evidence is needed on the beneficial and adverse effects, by opioid.

Abstract number: D-15
Abstract type: Poster

Enhancing the Quality of Continuous Sedation until Death: The Development of a Practice Protocol for Nursing Homes

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Objectives: Challenges inherent in the practice of continuous sedation until death (CSuD) appear to be particularly pervasive in nursing homes. We aimed to develop a protocol to improve the quality of the practice of CSuD in Belgian nursing homes.
Methods: A mixed methods design based on the Medical Research Council (MRC) Framework, including a systematic review and focus groups with 71 healthcare professionals identifying perceived barriers to the use of CSuD in nursing homes. Additionally, this protocol was reviewed and refined by another 70 healthcare professionals through ten expert panels.
Results: The final protocol was signed off by expert panels after two consultation rounds in which remaining issues were ironed out. The protocol encompassed seven sequential steps and is primarily focused on clarification of the medical and social situation, communication with all care providers involved and with the resident and/or relatives, the organisation of care, the actual performance of continuous sedation, and the supporting of relatives and care providers during and after the procedure. While consistent with existing guidelines, our protocol describes more comprehensively recommendations about coordination and collaboration practices in nursing homes as well as specific matters such as how to communicate with fellow residents and give them the opportunity to say goodbye in some way to the person who is dying.
Conclusions and implications: This study succeeded in developing a practice protocol for CSuD adapted to the specific context of nursing homes. Before implementing it, future research should focus on developing profound implementation strategies and on thoroughly evaluating its effectiveness.

Abstract number: D-17
Abstract type: Poster

Quality Indicators for Palliative Care of Older, Frail People and People with Dementia Using Routinely Collected Electronic Datasets: A Systematic Review

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Background: With population ageing, frailty and dementia are becoming increasingly common end of life considerations. Appropriate quality indicators (QIs) are needed to monitor the quality of care, detect areas of care for improvement, and learn from good practice across care settings. However, robustness of QIs for this purpose has not been evaluated.
Aim: To identify and assess QIs for the care of frail older people or people with dementia who are approaching the end of life. To recommend acceptable QIs for use with routinely collected electronic data across care settings.
Methods: Five databases were searched to February 2020, supplemented with reference chaining, for studies describing QI development. Each QI's psychometric properties (acceptability, evidence base, definition, feasibility, reliability, and validity) were extracted to inform assessment of utility. QIs were rated as robust, moderate or poor, categorised as process or outcome, and mapped against six palliative care domains. A shortlist of recommended QIs was generated based on robustness and appropriateness.
Results: 37 papers and 976 QIs were included. Of these, 780 (79.7%) were process and 199 (20.3%) were outcome QIs. Across care domains, QIs most often concerned physical aspects of care (n=492, 50.4%), with least focus given to spiritual and cultural aspects of care (n=19, 1.9%); 315 (32.3%) QIs were robust, and 220 were applicable using routinely collected data across care settings. The final shortlist of 71 QIs came from 7 studies.
Conclusions: Most QIs developed for palliative care of frail older people and those with dementia lack the information needed for practical use and are not designed for use with routinely collected electronic datasets at a population level. Routine data and robust QIs are crucial for enhancing our understanding of care provided to this population.

Abstract number: D-18
Abstract type: Poster

'Fighting for Life': A Drama Inspired by a True Story Exploring the Health, Social and Palliative Care Needs of Older People

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Aim: The 'Fighting For Life' drama is inspired by the true experiences of the Findlay family in their efforts to get appropriate care for their elderly parents towards the end of their lives. Their mother had dementia and their father had Motor Neurone Disease. The central aim is to promote critical thinking of the health, social and palliative care challenges of older people towards the end of their lives and address contemporary issues around person-centred care.
Design, methods and approach: The drama has been written by an award-winning professional playwright. Professional actors read from the script in radio-style. The roles are Joan (mother), Jim (father), Sandra (daughter) and two actors playing a Consultant, GP, Counsellor, Social Worker and Nursing Home Manager. Each performance is followed by a question-and-answer session involving an expert panel and a family member. It premiered in January 2018 at the Marie Curie Hampstead Hospice with subsequent performances at a variety of venues across the UK. Over 1,000 people have seen it including health, social and palliative care professionals, researchers, clinicians, family carers, decision-makers and representatives from the voluntary and charity sectors. Due to the pandemic, the drama has switched to online performances. Website: www.fightingforlife.org.uk
Results: The drama was a finalist in the Patient Experience Network National Awards 2018. Feedback from audiences have been collected. *"It* persuaded me to change my thinking and behaviour toward those I am caring for that have dementia" (healthcare professional) also "Powerful" "Emotional" "Excellent Discussion"
Conclusion/lessons learned: Presenting a true story through drama has provided a unique and powerful way to reach audiences on emotional and practical levels. It has provided a supportive and learning environment to enable discussion of difficult issues around healthcare, social care, palliative and end of life care for older people.

Abstract number: D-19
Abstract type: Poster

"And then, to Be Honest, it Has been Clear Even for the Oldest Granny" – Ageism in End-of-Life Care. A Qualitative Content Analysis Combined with Linguistic Conversation Analysis

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Background: Besides the categories of gender and ethnicity, age is one of the most important social categories. With increasing age, there are special needs and particularities with regard to care. Furthermore, underlying images of age and ageing can become recognisable in language.

Aim: The aim of the study was to identify aspects of communication, self-determination and decision-making issues with older patients as well as to evaluate the language used by health care professionals to describe older and younger patients and thus to reconstruct (implicitly) underlying images of age and ageing.

Methods: A secondary analysis of 51 interviews with health care professionals (hcp) about the use of sedative drugs in specialized palliative care. A structured and summarizing qualitative content analysis was combined with a linguistic conversation analysis. Older patients were defined as $\geqslant 60$ years and younger patients < 60 years.

Results: The content analysis showed that aspects of communication and information on treatment, relating to the use of sedative drugs are considered more important and are addressed earlier for younger palliative care patients. In relation to the conversation analysis, the comparison between younger and older patients showed a more frequent use of indefinite articles, metonymies, objectifications, generalisations and paratactic links for older patients.

Conclusion: The results indicate age stereotypes and negative age perceptions of hcp. Derogatory language towards older patients (e.g. "elder speak") is one manifestation of ageism. This can potentially lead to disadvantageous effects on clinical practice for older patients and should be taken seriously and be reflected upon intensively.

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Funding: None.

Abstract number: D-20
Abstract type: Poster

Meaning of 'Good Death' for People with Dementia: An Online Quantitative Survey for Bereaved Families and Medical Professionals

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Background: The meaning of 'good death' for individuals with dementia is unclear.

Aim: To clarify which components of good death are important for people with dementia and to conceptualise good death through an explanatory factor analysis.

Methods: In 2019, we conducted an online questionnaire survey that included a total of 618 bereaved family members of people with dementia, and 206 physicians, 206 nurses, and 206 care workers involved in dementia care. We asked about the importance of 44 items identified from previous qualitative interviews as components of 'good death' for people with dementia, assuming that the respondents themselves had dementia.

Results: As this was an online survey, the response rate was 100%, and a total of 1236 participants were analysed. For the bereaved family members survey, 78% of patients were aged >80 years, there were 63% females, and the places of death were hospitals (66%), care homes (20%), and home (13%). The top five items that the bereaved families indicated as important were 'a peaceful death' (97%), 'being free of pain and physical distress' (97%), 'being free of psychological distress' (96%), 'kept clean' (96%), and 'receiving necessary daily living support' (96%). The lowest items were 'receiving care from family' (53%), 'living with faith' (54%), and 'remaining in the memory of others after the death' (67%). An exploratory factor analysis identified the following three factors as the concepts of good death for people with dementia: 'comfort, security, and safety'; 'relationship' and 'autonomy'. We found only small differences between opinions of the bereaved family members and medical professionals.

Conclusion/Discussion: The concept of good death in people with dementia was consolidated into three domains: 'comfort, security, and safety'; 'relationship' and 'autonomy'. This study was supported by JSPS KAKENHI (Grant Number JP16KT0001).

Abstract number: D-22
Abstract type: Poster

Using Person-centred Outcome Measures to Enable Shared Decision-making and Improve Outcomes of Care for People with Dementia and Their Family Carers: A Systematic Review

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Background: Comprehensive assessment and shared decision-making are vital for person-centred care. Person-centred outcome measures (PCOMs) may support assessment and shared decision-making around treatment, but there is little evidence in dementia care. We aimed to understand how PCOMs enables shared decision-making between the person with dementia, family, and practitioners.

Methods: A theoretical model of shared decision-making underpinned the methods. Search terms were developed using other systematic reviews and in collaboration with an information specialist. Four research databases were searched. We quality appraised studies using the Mixed Methods Appraisal Tool. A narrative synthesis was conducted to identify themes on shared decision-making mechanisms to improve outcomes. The findings informed a logic model to detail the processes to using PCOMs and linkages between the context of care, mechanisms of impact on outcomes and implementation processes.

Results: Ten studies (12 articles) met eligibility, involving 1064 participants comprising people with dementia mainly in long-term care, family, and practitioners. Overall, n=6 studies met at least 4 of 5 quality criteria, indicating high quality evidence. PCOMs were used mainly to identify symptom (n=6). Mechanisms of impact include: 'Knowing the person' with dementia, 'identifying problems, priorities for care and treatment and goal setting', and 'evaluating decisions'. These impacted on outcome of function and activities of daily living.

Conclusion: The logic model details how PCOMs could enable comprehensive assessment and shared decision-making to improve outcomes. Key to using PCOMs involves the person with dementia, family and practitioner working together to complete the assessment to know the person with dementia which could empower expression of priorities for care. However, most of the evidence is in long term care, with little understanding of using PCOMs with people with dementia at home.

Abstract number: D-23
Abstract type: Poster

Prevalence and Factors Associated with Unfavourable Interventions in the Last Year of Life of People with Dementia: A Systematic Review with Narrative Synthesis

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Background: Dementia, a progressive disease that results in death, has been identified as a global health priority. Several quality indicators for end of life dementia care have been proposed, including unfavourable interventions.

Aim: To identify, critically appraise and synthesise evidence on the prevalence and factors associated with five unfavourable interventions for people with dementia in the last year of life: artificial feeding, late palliative care, hospital admission, emergency department(ED) attendance, and hospital death.

Methods: Four electronic databases and grey literature were searched. Studies reporting prevalence and factors associated with the five unfavourable interventions in adults over 60 with dementia were included. Study quality was assessed using QualSyst tool. Strength of evidence was determined based on quality, quantity and consistency of findings. Results were narratively synthesised.

Results: Of 9528 publications identified,46 met the inclusion criteria, largely retrospective cohort studies from USA and Europe. Median prevalence(IQR) for unfavourable interventions were: artificial feeding 63%(51-67%), late referral to palliative care 32%(12-50%), hospital admission 44%(30-61%), ED attendance 50%(20-73%), death in hospital 28%(18-35%).

A range of individual (lower education, lower socioeconomic status), illness-related (diagnosis of dementia compared to cancer), and environmental factors (no palliative care input, time further from present year) were associated with increased likelihood of unfavourable interventions. All evidence was graded low, except for moderate evidence for higher care home bed availability and year of death more recent being associated with lower likelihood of hospital death.

Conclusion: Unfavourable interventions at the end of life are prevalent in people with dementia. Palliative care and care home bed availability should be considered in dementia service development. Research from lower income countries is needed.

Abstract number: D-24
Abstract type: Poster

Co-creation of a DEDICATED Approach to Palliative Dementia Care

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Aims: Nursing staff play a key role in providing palliative care for people with dementia. Development of their palliative care competences may support timely recognition and addressing of individual needs of persons with dementia and their family caregivers. In the DEDICATED (Desired Dementia Care Towards End of Life) project, we aim to develop materials to support nursing staff in providing palliative dementia care.

Design, methods and approach taken: DEDICATED is a 4-year project, which started in 2017. Our initial studies concerned a needs assessment, mapping the perspectives of nursing staff, family caregivers and people with dementia (scoping review, secondary data analyses, surveys and in-depth interviews). Using these studies as a starting point, we initiated an iterative co-creation approach (from October 2019) involving nurses ($N = 8$), dementia case managers ($N = 4$) and nurse educators ($N = 4$) in the development of a DEDICATED-approach. These 'ambassadors' were also trained to disseminate the approach within their care teams and in nursing curricula.

Results: The co-creation process resulted in a number of support materials, related to the themes extracted from the initial needs assessment. The themes concerned: 1) awareness of a palliative approach in dementia, 2) getting to know each other, 3) end-of-life communication and 4) dealing with pain and challenging behaviours. For example, materials involve practice guides, animations and communication aides.

Conclusion / lessons learned: The support materials that resulted from the co-creation process and the ambassadors' training are currently being pilot tested and evaluated by DEDICATED-ambassadors and their colleagues. First reactions regarding the DEDICATED-materials are positive, and nurses and nurse educators are eager to use the materials. Future research will point out whether the DEDICATED-approach, implemented by care teams and educators, can improve nursing competences in palliative dementia care.

Abstract number: D-26
Abstract type: Poster

Interprofessional Collaboration Approaches in Palliative Dementia Care: A Scoping Review

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Background: Adequate palliative care (PC) improves quality of life (QoL) of people with dementia. As different disciplines are involved in PC, interprofessional collaboration (IPC) is important to preserve coordination and continuity of PC. To our knowledge, up to date, no review has been conducted on IPC approaches used in palliative dementia care.

Aim: The aim of this study was to provide an overview and explore components of existing IPC approaches in palliative dementia.

Methods: We performed a scoping review and applied the Johanna Briggs Institute Reviewer's manual and PRISMA guidelines to perform and document the search, screening, and inclusion procedures. The search was conducted in three databases (PubMed, CINAHL, and PsychInfo). Two reviewers independently performed the screening of all identified articles assess the inclusion criteria, and the content analysis of included articles to identify the components.

Results: In total, 18 articles were included. The content analysis revealed four components: *Content, Cooperation, Communication, and Collaborators*. Regarding content, the frequently reported topics embraced behavioral and pain management, and end-of-life (EOL) care. In order to perform these health tasks, diverse actors were involved (disciplines, family members, and people with dementia) in cooperation processes i.e. having shared goal, monitoring symptoms, conducting shared-decision making (SDM), executing advance care planning (ACP) and coordinating care. To ensure cooperation among these actors, communication skills, channels, documents, and short communication lines were used.

Conclusion: IPC approaches in palliative dementia care aim to improve QoL through involving diverse collaborators and compromising holistic care, person-centred care, SDM and ACP to manage symptoms and provide EOL care.

Abstract number: D-27
Abstract type: Poster

Perspectives of Community-residing Older People Living and Dying with Multimorbidity on their End-of-Life Care Needs: A Scoping Review

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Background: Older people with multimorbidity (OPWMM) are projected to be the main recipients of Palliative Care (PC) in the coming years, yet little is known about their perspectives on their PC needs.

Aim: This scoping review aimed to identify the extent and nature of existing evidence on the needs that OPWMM living in their usual place of residence find important at end of life.
Design: A scoping review across 4 databases was undertaken from inception to September 2019. Studies were included which reported on OPWMM or proxy views on their PC needs. MM was defined as the coexistence of two or more long-term conditions. Findings were thematically analysed using the components of a PC holistic assessment: physical, psychological, social, spiritual and practical.
Findings: Of the 818 unique articles, 27 studies were eligible for inclusion; quantitative (N=15), mixed methods (N=3), and qualitative (N=9). Needs were identified across all domains. Across all papers physical/function needs were reported most and while unmet needs across non-physical domains were identified, less analysis and discussion were undertaken. Quantitative studies frequently drew on PC multi-dimensional measurement tools, yet primacy given to reporting on physical needs. Mixed method and qualitative studies provided detail on OPWMM's expressed needs, detailing needs across all domains. Managing psychological symptoms, maintaining social connections, being informed about care, and practical issues of accessing and receiving good quality continuous care with trusted people were prioritised by older people. Where reported, older peoples expressed needs often differed from staff views of their needs.
Conclusion: There is a gap between the important PC needs as expressed by OPWMM and those that are prioritised in reporting in the literature. Assessment and outcome tools need to be tailored to this population and used by services to meet all PC domains, to ensure quality care across living and dying.

Abstract number: D-29
Abstract type: Poster

Being There: The Lived Experiences of Older Cancer Patients in China

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Background: China's population is ageing rapidly, and there is an increase in the mortality rate of cancer among the aged population. Providing appropriate palliative care for older cancer patients is becoming a pressing public health concern. However, little is known about their needs at the end of life.
Aims: To provide a deep understanding of the lived experiences of older cancer patients in China and uncover their needs for better palliative care.
Methods: Quantitative design using Heidegger's interpretive phenomenology to enable focus on subjective experience. Open-structured, in-depth, face-to-face interviews were conducted over 4 months. Participants were recruited using purposive sampling, including 10 cancer patients aged 60 + with a range of cancer diagnosis.
Results: Findings demonstrate that participants experienced a number of existential challenges while 'being there'- having cancer. These existential challenges included anxiety, depression, sadness, vulnerability, and isolation. In particular, the illness had affected their ways of being-in-the-word. Participants identified themselves differently from what they were in the past due to the loss of physical images and changes in their roles in the family and the social networks. Cancer patients also felt that "Others" could not understand them and tended to self-isolate and avoid sharing the feeling with others. Given the loss of previous self-image and places in the world, some patients redefined their goals and positions and changed lifestyle and values. They also coped with the distress in different ways.
Conclusion: The dying of cancer patients is not something which care providers can experience in a genuine sense. This study identifies the existential challenges of older cancer patients. These findings have valuable implications for care providers when designing optimal care for the patients.

Abstract number: D-30
Abstract type: Poster

Factors Leading to Terminal Hospitalization of Residents of Residential Social Care Facilities for the Elderly People in the Czech Republic

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Background: In the Czech Republic the number of people that die as residents of care homes for the elderly increases. Some of those residents die in hospital (around 45 % of deceived residents (ÚZIS, 2019; ČSÚ, 2019)). It is arguable if those hospitalizations contributed to the quality of life of residents; also if those were in line with the wishes of those residents.
Aims: Aims of the study are twofold. 1) To understand factors leading to a decision about terminal hospitalization from the point of view of nurses and social workers in the CZE. 2) To understand a relation between decision-making about hospitalization and terminal hospitalization.
Methods: We conducted semi-structured interviews with 12 nurses (in 2018) and 5 social workers (in 2021; in the group of social workers we achieve theoretic saturation). Interviews were transcribed verbatim. Data were analyzed by the thematic analysis method using Atlas.ti software.
Results: 6 groups of factors contributing/leading to hospitalization during which resident of a care home dies, were found:

1) Options that the facility has concerning technical equipment; infusion administration; diagnostic options; medications
2) Availability of medical decision-making
3) Defensive approach of personal while making the decision about terminal hospitalization
4) Lack of care planning
5) Sudden unpredictable acute conditions
6) Exercising the will to send/go to a hospital

Terminality of life seemed to have no impact on decision-making itself.
Conclusion: Usually multiple factors from different groups lead to hospitalization in which residents die. Although findings are mostly in line with those of other states, the CZE seemed to have some specifics, i.e. small competencies of nurses, a problematic transitions care planning and advance care planning in care homes, problematic use of a living will in care homes, professional sectoralization rather than the multidisciplinary approach in terminal hospitalization decision-making.

Abstract number: D-32
Abstract type: Poster

Timely Short-term Specialized Palliative Care Service Intervention for Frail Older People and Their Family Carers in Primary Care: Development and Modelling of the Intervention Using Theory of Change

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Background: Short-term integrated palliative care models have been advocated for older people with frailty and multimorbidity in the community. It remains unclear what these interventions entail and how they can be best implemented.

Aims: To develop and model a timely short-term specialized palliative care service intervention for frail older people with complex needs and their family in primary care, detailing intervention components, outcomes and preconditions needed for implementation, using a novel theoretical approach.

Methods: Observational study informed by the UK MRC Framework for complex interventions integrated with a Theory of Change (ie. hypothetical causal pathway to impact) approach. We synthesized evidence from a systematic review, semi-structured interviews with older people (n=3), two group discussions with older people (n=11), one group discussion with family (n=8) and Theory of Change workshops with professional stakeholders (n=45).

Results: We identified long-term outcomes on the level of frail older people and family and the preconditions to achieve them e.g. service providers are willing and able to deliver the intervention. The intervention components included implementation components, e.g. training for service providers, and a core component, i.e. provision of timely short-term specialized palliative care by a specialized palliative home care nurse. The latter includes: short-term service delivery; collaborative and integrative working within primary care; delivery of holistic needs- and capacity-based care; person-centered and family-focused; and goal-oriented pro-active care.

Conclusions: The Theory of Change approach allowed us to identify multiple intervention components targeting different stakeholders to achieve the desired outcomes. It also facilitated a detailed description of the intervention which aims to increase replicability and effective comparisons with other interventions.

Funding: FWO

Abstract number: D-33
Abstract type: Poster

What Are the Palliative Care Symptoms, Concerns and Wellbeing of Older People with Frailty with Complex Care Needs who Are Discharged from Hospital to Home?

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Background: Older people with frailty often have complex care needs and many have hospital admissions in the last years of life, yet, our understanding of their specific needs at hospital discharge is limited.

Aim: To describe the palliative care symptoms, concerns and wellbeing of older people with frailty with complex care needs who are discharged from hospital to home.

Methods: A cross-sectional study using baseline survey data of a pilot randomized controlled trial. Hospital health staff identified patients according to criteria: aged 70 years or over, Clinical Frailty Score 5 – 7, unresolved or complex symptoms or problems and planned to be discharged home. Patients were interviewed by the researcher prior randomisation, using a structured questionnaire that examined socio-demographic characteristics, palliative care symptoms, concerns and wellbeing, using the Integrated Palliative Care Outcome Scale (IPOS) and ICECAP Supportive Care Measure. Descriptive statistics were used.

Results: We surveyed 37 older people with frailty, 49% women and mean age 84 years. Symptoms rated as causing severe problems were weakness (46%), poor mobility (40%) and pain (30%). Fifty-four percent of the patients felt anxiety and 61% felt depressed. Seventy-five percent reported that their family felt anxious or worried about them. Of the 17 IPOS items, 86% of the patients rated at least one symptom or concern as causing severe problems, and 41% rated at least five symptoms or concerns as causing severe problems. Eighty-seven percent of the patients expressed to feel supported, 84% to be able to maintain their dignity, and 73% to be with people who care about them most of the time.

Conclusions: This study identified that a large proportion of older people with frailty at hospital discharge were severely affected by a range of symptoms and problems in multiple domains. This group should be considered for referral to specialist palliative home care services.

Funding: FWO

Abstract number: D-34
Abstract type: Poster

Night Sedation Prescribing and Administration Practices in a Specialist Palliative Care Service

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Background: Insomnia is common in patients requiring Specialist Palliative Care (SPC), with an estimated prevalence of 29%-59%. Insomnia is a distressing symptom which can impact a patient's quality of life. However, medications used for night sedation increase the risk of falls and potential patient harm, particularly in older adults.

Methods: An audit of night sedation prescribing and administration practices was performed. Patients admitted to an inpatient unit (IPU) for $>$ 4 weeks or patients admitted to community palliative care (CPC) services for $>$ 3 months from March-September 2020 were included. 32 inpatient charts and 47 community patient charts were reviewed. The majority of inpatients (56%) and community patients (80%) were $>$65 years. 31% of inpatients had a background of delirium or cognitive impairment on admission. Most inpatients (78%) and community patients (89%) were ambulatory on admission. A sleep history was documented in 78% of inpatients, and 77% of community patients. 22% of the inpatients were on a Z drug on admission, with a further 31% prescribed a Z drug during admission. Only 4% of community patients were on a Z drug on admission with a further 9% prescribed a Z drug during CPC admission. Of those prescribed night sedation in the IPU, 94% were also prescribed a benzodiazepine, 76% were prescribed a regular opiate medication, and 47% were prescribed an anti-psychotic medication. Older adults were not prescribed night sedation more frequently than younger adults in the IPU (n=4/18 vs n=6/14, p=0.6802). In 23% of patients prescribed night sedation (n=4/17), 31% of doses were administered after midnight.

Conclusion: Z drugs and BZD are commonly used for night sedation in the IPU. Efficacy should be frequently reviewed as well as timing of administration, to minimise side effects and risk to this vulnerable patient cohort.

Abstract number: D-35
Abstract type: Poster

The Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem) Italian Version: Translation and Cognitive Debriefing

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Background: The Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem) is a version of the IPOS developed for professional caregivers working in NH, aimed to properly assess the palliative care needs of patients with dementia. The original tool was created in the UK and there is not an Italian version available.

Aim: To translate the IPOS-Dem in Italian and adapt it to our cultural environment.
Methods: Following the EORTC guidelines for translation and adaptation of questionnaires, a forward backward translation process was performed involving a professional translator whose first language was English, and the Italian researchers. A proof reading phase followed, involving the original IPOS -Dem authors. The final IPOS-Dem Italian version was tested in a qualitative assessment study aimed to adapt it to the Italian NH setting. This study included a focus group (FGM) with 5 professionals working in an Italian NH and 6 individual interviews with caregivers involved in the care of people with severe dementia. All the events happened during 2020 and, despite the limitation due to the COVID pandemic, could be performed with the physical attendance of the participants.
Results: All participants involved in the FGM and in the interviews reported positive feedback about the tool. It was defined as useful, clear and applicable in Italian NH settings. It helps in the multidimensional assessment of cognitive impaired patients, in the individual care planning, allows to measure the explored items and follow them up overtime, providing a good insight on the outcomes of the interventions.
Conclusions: IPOS-Dem is now available in Italian language, it confirmed its properties as an appropriate, acceptable and useful assessment tool in our cultural context. A full validation study remains needed in order to obtain a full validation.

Abstract number: D-36
Abstract type: Poster

Patients' Preferred Place of Death: Patients Are Willing to Consider their Preferences, but Someone Has to Ask Them

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Background: End-of-life preferences are not always in line with care at the end-of-life. As a result, dying at the preferred place of death (PPD) is not always achieved.
Aim: The aim of this study is to identify factors associated with patients' PPD and change in PPD.
Methods: We performed a secondary analysis, based on 230 acutely hospitalised patients (⩾65 years) who participated as control patients in a stepped wedge randomised controlled trial. Data was collected at 4 follow-up moments , through patients' electronic medical record and questionnaires. We used multivariable logistic regression and multinomial logistic regression to calculate associations between patient characteristics and PPD.
Results: The mean age of participants was 80.7 years and for 35% organ failure was the main diagnosis. At baseline, 44.6% of the patients had no PPD (yet). Previously admitted patients were most likely to prefer to die at home (home vs no preference: OR 2.38 (95% CI 1.15-4.92)), (home vs care facility: OR 3.25 (95% CI 1.15-9.16)). Suffering from multiple chronic diseases was associated with having a care facility as PPD (care facility vs no preference: OR 1.33(95% CI 1.09-1.61)), care facility vs home: OR 1.21(95% CI 1.00-1.47))). The proportion of patients deceased within six months ranged from 30%-38% and was not statistically significant different between preference groups. 33 of 63 patients changed PPD during follow-up, mostly if they initially had no PPD (OR home vs no preference: 0.005 (95%CI ⩽0.001-0.095)) and in case of poorer self-rated well-being (OR 1.82(95% CI 1.07-3.08)).
Conclusion: Patients often have no PPD (yet), even when death is near. Our finding that patients change from having no PPD to having a PPD demonstrates the willingness to consider this topic. Knowledge about factors that are associated with the PPD could help healthcare providers identifying patients who are unaware of their PPD in order to introduce this topic and trigger patients' awareness.

Abstract number: D-37
Abstract type: Poster

Compare the Patients in Palliative Care with Pressure Injuries with and without Diabetes Type 2

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Aim: The aim of this study was to compare the factors that are effective for the treatment, recovery of pressure injury (PI) in palliative care (PC) patients with diabetes type 2 and without diabetes type 2.
Materials and methods: Patients were grouped according to diagnoses, First group were PI patients with diabetes type 2, second group of patients without diabetes type 2. The comparison was made of changes in wound stage in the groups.
Results: PI was present in all 139 patients during hospitalization, 51 patiant with diabetes type 2. 88 patients without diabetes type 2. Full recovery was determined in 35/88 (40.%) patients with PI in First group of patients, Improvement in PI stage was seen in 44 pacients in first group of pacients. Worsening PI stage was observed in 9/88 In second group of patients Full recovery wes determained 19/51 patients, Improvement in PI stage was seen in 26/51 pacients, Worsening PI stage was observed in 6/51 pacients. The Karnovsky Performance Score and Glasgow Coma Score of fully recovered patients were determined to be higher, and no statistically significant difference was seen in respect of age.
Conclusions: PC patients are prone to PI due to many chronic diseases. no statistically significant difference was seen in PI patients with and without diabetes type 2.

Abstract number: D-38
Abstract type: Poster

Implementing the '7 Day Rule' for Hospital Anticipatory Care Plans

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Background: A study from Cambridge in 2010 found that introduction of a Universal Form of Treatment Options as an alternative to Do Not Attempt Cardiopulmonary Resuscitation(DNACPR) orders, significantly reduced frequency/severity of harms in patients with a DNAPCR decision, and increased number of patients identified early as requiring palliative care, with no change in mortality.
Aim: To encourage completion of Hospital Anticipatory Care Plan(HACP) in patients acutely admitted under 2 care of the elderly consultants after day 7 of admission.
Method:

1. Retrospective audit of patients admitted under 2 consultants May-July2019, to identify number of patients:
   a. admitted ⩾7days
   b. with HACP completed
   c. with HACP deceased on that admission
   d. deceased at follow-up date(21/09/2019)
2. Re-audit 2 weeks of admissions to identify change in practice when blank HACP forms are put in patient's casenotes.

Results:

99patients:

a. 73% admitted ⩾7days.
b. 28had HACP during that admission.
c. All 11patients that died during their admission had HACP.
d. 29patients deceased at follow-up.

Re-audit – 42patients:

a. 74% admitted ⩾7days.
b. 18 patients had HACP in their notes to be completed after 7days. 2 were completed(11%). 8 patients had HACP during their admission. All patients with HACP had DNACPR. 8 patients had only DNACPR.
c. 0patients died during admission.
d. 10patients deceased on follow up date(21/4/20).

Discussion/Conclusion: It is reassuring that patients dying in hospital have appropriate DNACPR/HACP documentation. Implementing the HACP 7 day rule has not been successful in this PDSA cycle, placing the HACP document in the patient's notes did not prompt completion.

However, during the COVID-19 pandemic, many patients had treatment escalation plans completed on admission and we are in the process of re-auditing this (results will be available for presentation).

Abstract number: D-39
Abstract type: Poster

Differences between Palliative Care Outcomes Reported by Nurses, Patients and Cognitive Impaired Patients' Relatives in Spanish Nursing Homes

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Background: It is expected that a high percentage of people in Spain will die in nursing homes, but the quality of care at the end of life in these centers has not been deeply analyzed. Aims: Determine the differences in palliative care outcomes between nurses, patients, and family caregivers of cognitive impaired patients in Spanish nursing homes.

Methods (design, data collection, analysis): Descriptive cross-sectional study. Palliative patients were identified with the NECPAL tool from 8 nursing homes in southern Spain in January 2020. Independently, patients, relatives of patients with cognitive impairment and nurses completed the Palliative Outcome Scale (POS). T Student test for correlated samples was used to check whether there were differences in the scores between nurses, patients, and family caregivers of cognitive impaired patients and Pearson correlation test was used to evaluate correlation between all participants scores.

Results: 149 cases were analyzed, of which 67.9% were women with a mean age of 84.46 years (SD = 9.12). Only in some cases POS score was available for nurses-patients (n=39) or nurses-relatives of patients with impairment with (n=27). The total POS score in professionals does not correlate significantly with that given by patients (r = - .040; p =. 825), but it does with the perception of relatives of patients with cognitive impairment (r = .775; p =, 000). Patients without cognitive impairment reported more pain (p = .025), more anxiety regarding family members (p = .033) and less information disclosed (p = .003) than nurses. The professionals agreed with the cognitive impaired patients' relatives in the assessment of pain and other symptoms but stated that the patients were more concerned about their illness and treatment (p = .045).

Conclusion / discussion: Nurses perception of palliative care outcomes is important, but it cannot replace the perception of the patient or the family.

Abstract number: D-40
Abstract type: Poster

Cholinesterase Inhibitor Use in Patients with Dementia Admitted to a Palliative Care Unit

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Background: Dementia is becoming a common diagnosis to manage in palliative care. Patients admitted to a palliative care unit (PCU) with dementia may be on a cholinesterase inhibitor (CHEIS). CHEIs can be considered an unnecessary burden in the advanced stages of dementia. Potential harms of continuing CHEIs in patients with advanced dementia and on a CHEI include drug interactions, pill burden, dysphagia, cost of medication and a misunderstanding of a patient's goals of care. Current guidelines suggest that patients with dementia on CHEIs should discontinue their CHEIs by taper when indicated.

Aims: This study aims to define the prevalence of patients admitted to a palliative care unit with dementia on a CHEI and to determine whether these patients were tapered off their CHEIs according to current deprescribing guidelines.

Methods: This was a descriptive retrospective chart review of patients admitted to a PCU with dementia on a CHEI from January 2015 to June 2019. Data was collected to determine if and how patients were tapered off their CHEIs.

Results: A total of 36 patients were admitted to the PCU with dementia on a CHEI (prevalence of 2.3%). For 31 of these patients, their CHEI was discontinued, only 9 of which had a taper. Of the 24 patients who discontinued their CHEI suddenly, 10 patients had an order to discontinue their CHEI in the last 2 days before their date of death.

Conclusion: This study suggests that although patients admitted to a PCU with dementia have their CHEI discontinued, the discontinuation was done without a taper. More so, it appears in many cases the CHEIs were continued through the active stage of dying, which may relate to family wishes or a sudden decline to functional status. Considering the shorter length of stay for these patients on the PCU, it is surprising that CHEIs were not tapered earlier in the illness trajectory.

Abstract number: D-41
Abstract type: Poster

Information Needs and Preferences in Nursing Home Patients with and without Cognitive Impairment who Are at the End of Life

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Background: Proper end-of-life advanced care planning in nursing home must be based on patients and family's information needs and preferences.

Aims: Describe information needs and preferences of nursing homes patients at the end of life and their families, and the differences between patients with or without cognitive impairment.
Methods: Descriptive cross-sectional study. Palliative patients were identified with the NECPAL from 8 nursing homes in southern Spain in January 2020. Nurses completed an ad hoc form in which they were asked to indicate the degree of information received by patients and families, the type of information and the information preferences. Cases with and without cognitive impairment were compared with Student's T-test.
Results: 124 cases (66.1% women) with a mean age 84.69 years were analyzed. 46% of the patients showed cognitive impairment. 65.7% of the patients without cognitive impairment and 31.6% of the patients with cognitive impairment received total information about their situation. 94.7% relatives of patients without cognitive impairment and 91.0% relatives of patients with cognitive impairment received total information about patients' situation. Regarding preferences, 64.2% of patients without and 12.1% of patients with cognitive impairment stated that they wanted to be totally informed. 35.8% of the patients without cognitive impairment and 79% of the patients with cognitive impairment did not show preferences on this regard. Statistically differences were found between the information provided ($p < .01$) and preferences ($p < .01$) between patients with and without cognitive impairment. The information that is less frequently provided to the patient / family is related to the prognosis; 80.6% of patients without cognitive impairment and 89.5% relatives of patients with cognitive impairment were informed about prognosis.
Conclusion: Nursing home professionals need to explore deeply the information preferences of patients and families.

E Posters Education and Advocacy

Abstract number: E-01
Abstract type: Poster

Informing the French Public about the End-of-Life with a MOOC Tool

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Aim: A MOOC is a flexible way to broadcast educational content provided by professionals. By diverting the MOOC from its training role function and taking advantage of its functionalities, we have innovated in providing information to the general public about the complex subject of end-of-life. In 2020, MOOCers twice had the opportunity, at their own pace and without time constraints, to learn about their rights, to better understand the issues of the end-of-life both in France and abroad and to interact with others. The aim of this communication is to present the MOOC content and how it can be an effective information tool for reaching a large population on and for promoting discussion around the end-of-life.
Design and methods: The MOOC is divided by 8 sequences (context, communication, palliative care, rights, procedures, treatments, hydration and nutrition, end-of-life issues). Each sequence allows people to discuss together on end-of-life via structured-forum and open chat. At the beginning and at the end of each MOOC session, MOOCers completed questionnaires on their experiences with MOOCs and their expectations in relation to our MOOC.
Results: Approximately 12,700 MOOCers took part in the two MOOC sessions. Among the respondents of questionnaires (10% of MOOCers), 83% are women (average age=51 from 13 to 91), 47% are professionals, 53% are caregivers, volunteers, patients, or citizens. These data show that the MOOC reached a representative sample of the population. Around 1,000 discussion threads with an average of 4 to 5 interactions between MOOCers suggest that the MOOC is a good means for MOOCers who wished to share their questions, and testimonies.
Conclusion: Unlike a traditional information tool such as information campaigns, the MOOC offers the advantage of interaction between the designers of the information delivered and MOOCers. It is therefore possible to ensure that the messages thus disseminated are understood and assimilated.

Abstract number: E-05
Abstract type: Posters

Development of Discipline-specific Palliative Care Competencies in Alberta Using a Consensus-based Decision-making Process

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Background: Establishing palliative care early in an illness trajectory is beneficial to the patient and requires services to be delivered in both generalist and specialist settings by multidisciplinary teams. However, evidence suggests most health care providers (HCPs) have received limited education in palliative care and are not adequately trained to provide it.
Aim: This project is to describe the development of province wide discipline-specific palliative care competencies.
Methods: Competencies were developed in four steps:

(1) conduct a comprehensive review of literature including other provincial, national and international palliative care competency frameworks;
(2) establish a steering committee and advisory working group and formulate HCP-specific working groups, including academics, employers and professional regulatory bodies;
(3) establish a competency framework; and
(4) develop provincial HCP-specific palliative care competencies.

The Consensus-Oriented Decision-Making Model and a modified Delphi technique were utilized to achieve agreement.
Results: A total of 185 individuals comprised a steering committee, an advisory working group, and 15 palliative care competency working groups. A greater than 75% agreement was achieved at the end of each domain discussion, resulting in a framework of ten domains and three levels of palliative care expertise. Further consensus of palliative care competencies and self-assessment tools was obtained through an average of six one-hour meetings or three rounds of Delphi surveys for each of the 15 HCP groups.
Conclusion: These specific palliative care competencies allow HCPs to identify the skills, knowledge and attitudes required when providing palliative care. Additionally, these tailored palliative care competencies can be used as a resource to inform and guide academic curricula, professional development, professional regulatory bodies, continuing education programs and employers representing the entire province.

Abstract number: E-06
Abstract type: Poster

Public perceptions of advance care planning: a scoping review including online resources and public consultation

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Background: Advance care planning (ACP) supports people to discuss and share values, goals and preferences for future medical care. Health and legal plans (e.g. proxy decision-maker) can be documented. ACP causes harm if poorly implemented or misunderstood by citizens.

Aim: A scoping review and public consultation explored what people understand about ACP, perceptions of online public information, and how to improve public messaging and engagement.

Methods: Joanna Briggs Institute method for scoping literature reviews and PRISMA-ScR guided a 10-year review (2011-2021). Databases were: Embase, PubMed, PsycArticles, the Cochrane library and CEBM Oxford. Public opinion databases; World Association for Public Opinion Research, Public Information On-line, European Society for Opinion and Marketing Research, and UK charitable databases were screened, plus hand searching key journals. Studies of communication with professionals were excluded leaving 15 papers. Public involvement team members reviewed UK (10) and international (10) public information websites. Public discussion groups (7) were held online with older people, relatives of care home residents, learning disability support workers, minority ethnic community leaders and advocates.

Results: Knowledge and awareness of ACP terminology, content, processes and purpose were low. Fears included 'tempting fate' by discussing death or incapacity, causing distress to family members, autonomy delegated to others, and problematic future prediction. Lack of trust in the system, diverse social norms among ethnic groups, and poor integration with other health plans (e.g for people with disability) emerged. Websites varied in readability and content, with inconsistency even in the same health system.

Conclusion: Public involvement and engagement are essential to ACP, but public information falls short. It needs to address key motivational factors and connect with what matters to people in diverse situations.

Funder: Marie Curie

Abstract number: E-08
Abstract type: Poster

Education on Palliative Care for Parkinson Patients: Development of the "Best Care for People with Late-Stage Parkinson's Disease" Curriculum Toolkit

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Background: Palliative care education among all stakeholders involved in the care of patients with late-stage Parkinson's disease is not adequate. In fact, there are many unmet educational and training needs as confirmed with a targeted literature review.

Methods: To address these needs we have developed the "Best Care for People with Late-Stage Parkinson's Disease" curriculum toolkit. The toolkit is based on recommendations and guidelines for training clinicians and other healthcare professionals involved in palliative care, educational material developed in recent research efforts for patients and caregivers with PD and consensus meetings of leading experts in the field. The final version of the proposed toolkit is the result of evaluation by external experts the feedback of which was statistically analysed with the chi-square test of independence. A sentiment analysis was also done.

Results: The toolkit is compliant with Kern's foundational framework for curriculum development, recently adapted to online learning. The statistical analysis of the online survey, aiming at toolkit evaluation from external experts (27 in total), confirms that all but one (nutrition in advanced Parkinson's disease) topics included, as well as their objectives and content, are highly relevant and useful.

Conclusions: In this paper, the methods for the development of the toolkit, its stepwise evolution, as well as the toolkit implementation as a Massive Open Online Course (MOOC), are presented. The "Best Care for People with Late-Stage Parkinson' s disease" curriculum toolkit can provide high-quality and equitable education, delivered by an interdisciplinary team of educators. The toolkit can improve communication about palliative care in neurological conditions at international and multidisciplinary level. It can also increase patients' and caregivers' health literacy and offer continuing medical education for healthcare providers.

Abstract number: E-09
Abstract type: Poster

The Effect of a Multidisciplinary Blended Learning Program on Healthcare Professionals' Knowledge in Palliative Care for People with Parkinson's Disease.

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Background: Parkinson's disease (PD) is a progressive degenerative disease without curative treatment perspectives. Palliative care for this population is still suboptimal. A key issue in this is that PD healthcare professionals, basically trained in neurology care, report a lack of knowledge and competences with regard to palliative care in PD. Several studies showed the need for improved education in this field.

Aims: The purpose of this study was to investigate the effect of a multidisciplinary blended learning on professionals' knowledge in palliative care for people with PD.

Methods: We used a pre-posttest study design. The sample consisted of 834 professionals from 45 regional ParkinsonNet networks of specialized PD professionals. The blended learning consisted of a 4-hour online e-learning followed by an (online) meeting in which the participating PD professionals discussed palliative care for PD. At least one expert professional from the field of palliative care was actively involved and present during the whole meeting. Primary outcome was participants' level of knowledge on a scale of 1-10. Secondary outcomes existed of familiarity with specialized palliative care services measured on a 5 - point Likert scale.

Results: We performed an interim-analysis in a small sample of 47 professionals (data regarding all participants will be analyzed in November 2021). Data on self-registered knowledge was not normally distributed and analysed with Wilcoxon signed rank test. Findings showed a median of 5 in the pretest and 6 in the posttest ($Z = -2.293$, $p = 0.022$). Analysis of respondents scores on the familiarity with specialized palliative care services showed a median of 2 and 3 in the pre- and posttest, respectively ($Z = -5.065$, $p < 0.001$).

Conclusion: This study suggests that a multidisciplinary blended learning program is effective in improving professionals knowledge in palliative care for people with PD.

Abstract number: E-10
Abstract type: Poster

The Last Aid Course and Minorities Need for Cultural Adaptation – A Pilot Project for German and Danish Minorities across the Border

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Aims: Most people wish to die in their own home. Many need help and support from family members or others in the last days. Last Aid course gives citizens knowledge about options of how to support the dying and they learn what they can do themselves. The overall goal of the project is to form a cross-border network to discuss cultural differences in relation to care and nursing at the end of life and discuss how these differences can be included in the last aid course for minorities at both sides of the boarder.

Methods: Three one-day workshops are planned for people from a variety of different organizations, nationalities and diverse cultural and religious backgrounds. During the workshops the participants will follow a last aid course and afterwards focus group discussions will be performed. The focus group discussions will be transcribed verbally and shall be analyzed based on interpretive description. Cooperation partners are the Medical Research unit in Sonderborg Denmark, the Katharinen Hospice in Flensburg Germany, Letzte Hilfe Deutschland gUG Germany and Dansk Folkehjælp Denmark. The project is funded by INTERREG,the South Jutland Hospital and the Katharinen Hospiz Flensburg.

Results: During the first contacts and the projects kick-off meeting in February the important role of cultural issues in end-of-life care and palliative care provision became evident. The results from the workshops and focus group discussions shall lead to cultural adjustments of the existing first aid course to address the needs of people with different cultural and religious backgrounds and minorities. Results from the project will be used to establish a larger following project covering the whole boarder region.

Conclusion: The project will contribute to;

i) more knowledge about end-of-life care in the public,
ii) improve palliative care provision,
iii) encourage the public discussion about death and dying,
iv) increase citizen participation.

Abstract number: E-11
Abstract type: Poster

Evaluating the Effectiveness of a Pilot 30-hour Basic Palliative Care Training Program in Malaysia

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Background: Delivering palliative care as a part of universal health coverage requires a critical mass of healthcare professionals that are able to deliver palliative care at the basic, intermediate, and specialist level. Basic training programs are important for increasing the health system's capacity to provide palliative care. Currently, only specialist-level training program are available in Malaysia.

Aims: To evaluate the effect of the training program on the participants' interest, knowledge, and their preparedness to deliver basic-level palliative care.

Methods: We developed a 30-hour training program for physicians without palliative care training. The training was conducted over 6 months using a mix of bedside teaching, case-based learning, hands-on practice, along with a mentor-mentee system.

To evaluate the effect of the training, surveys were conducted at 3 points: pre-training, at the completion of the training (post-training), and 3 months after the training (3-months post-training). The survey measured changes in the participant's interest, knowledge, and preparedness. The survey used a mix of True/False questions, and 5-point Likert scales (1 = lowest, 5 = highest). Pre-training and post-training results were compared to observe for the training effect. The post-training and 3-months post-training results were also compared to observe for sustained effects. Paired t-tests and Friedman's Two-Way Analysis of Variance by Ranks were used for analysis.

Results: 38 physicians participated in the training program. The results of the training are described below:

Category	Pre-training average score	Post-training average score	3 months post-training average score	Pre-training vs post-training (p-value)	Post-training vs 3-months post-training (p-value)
Interest in palliative care	4.05	4.24	4.22	0.033	0.414
Preparedness to perform a full palliative care assessment	2.82	3.86	3.85	<0.001	0.655
Preparedness to perform a full pain assessment	3.21	4.21	4.11	<0.001	1.000
Preparedness in assessing and managing patients with shortness of breath	3.05	3.83	3.96	<0.001	0.166
Preparedness in inserting subcutaneous port	2.87	4.03	4.00	<0.001	1.000
Preparedness in breaking bad news	3.39	4.03	4.19	0.001	0.655
Preparedness in discussing prognosis	2.87	3.86	3.93	<0.001	0.803
Preparedness in managing end-of-life	2.97	3.40	3.93	<0.001	0.655
Palliative Care Test Score	83.05%	93.1%	94.67%	<0.001	0.319

Conclusion: The results suggest that a basic 30-hour training program can be effective in improving the participants' interest, preparedness, and knowledge of palliative care. These improvements were also sustained for 3 months post-training. The learning methods and the mentor-mentee system used are effective and affordable methods that can be scaled up to train more healthcare professionals.

Abstract number: E-12
Abstract type: Poster

A New Last Aid Course in Easy Language for Mentally Handicapped People

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Aims: In order to enable people to participate in end-of-life care at home Last Aid courses have been started in Germany, Norway and Denmark in 2014/2015. Today 17 countries are members of the International Last Aid working group and the 2. International Last Aid conference was held in 2020. People with mentally handicap are also relatives of dying people and may experience death of others in their surroundings. The aim of the present work was to adapt the existing Last Aid course curriculum to fit the needs of mentally handicapped people.

Methods: A working group of Letzte Hilfe Deutschland gUG (the German Last Aid NGO) was established including experts from the fields of palliative care, education and work with mentally handicapped people. The multidisciplinary group worked using video meetings only due to the ongoing Covid-pandemic.

Results: Within the year 2020 the group revised the complete curriculum to suit the needs of mentally handicapped people while keeping the original course format with four modules with 45 minutes each. The four modules are about: 1. Dying as a normal part of life; 2. Planning ahead; 3. Relieving suffering; 4. Final goodbyes. The used easy language approach was based on: short sentences; easy language; well-known words; a clear structure; pictures explaining the writing and certain rules for the layout. The curriculum and the slide presentation for the course was proofread by people with mental handicaps and a specialised agency for easy language in order to receive the easy-to-read-logo from Inclusion Europe. Due to the restriction for classroom education the course has not been tested in practice yet. Pilot-courses are planned and will be started as soon as the actual Covid-restrictions permit classroom education again.

Conclusions: The working group has established an adapted Last Aid course curriculum and slide presentation for mentally handicapped people. The course will be pilot-tested soon.

Abstract number: E-13
Abstract type: Poster

Evaluation of a "Bitesize" Teaching Programme for Hospice Ward Nurses

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Aims:
- To establish a teaching programme for hospice ward nurses and healthcare assistants (HCAs), with sessions led by junior doctors and allied healthcare professionals.
- To design sessions in response to learning needs identified by clinical managers and participants.
- To increase participants' confidence in topics relevant to their regular clinical work.
- To create a friendly, informal learning atmosphere.

Design, methods and approach taken:
- Topics were initially selected with support from nurse managers and in response to knowledge gaps identified by formal clinical incident reports.
- Sessions were timetabled to maximise convenience for participants and took place on the ward to facilitate easy clinical cover for staff in attendance.
- The name 'Bitesize': sessions were short and digestible (20-30 minutes). Facilitators were encouraged to bring sweet treats to create a friendly learning environment.
- Participants completed written feedback to score their confidence pre- and post-session. Feedback also gauged the relevance of the content to clinical practice and invited suggestions for future topics.

Results:
- 14 sessions took place with a total of 70 attendees.
- 77% felt the sessions to be 'very relevant' to their daily clinical practice.
- 94% felt either 'confident' or 'very confident' on the topic after the session, compared with 30% feeling either 'confident' or 'very confident' beforehand.

Conclusions:
- The 'bitesize' teaching programme is an effective way to deliver accessible, relevant teaching to staff on busy wards.
- Session leaders and participants noted that the teaching has improved interdisciplinary interaction.
- When nurses were allocated to attend by the charge nurse in advance, participant numbers were higher.
- Limitations included reduced attendance due to staff absence and restrictions due to COVID-19 social distancing.

Abstract number: E-14
Abstract type: Poster

A Systematic Scoping Review of Postgraduate Remediation Programs in Palliative Medicine

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Background: Remediation may be defined as the 'deliberate practice of improving performance through practising tasks beyond one's comfort level under guidance'. Postgraduate remediation is extremely essential to produce competent palliative medicine doctors, given that medicine requires lifelong learning and education. However, due to differences in sociocultural and financial factors, coupled with the lack of research on key elements of a successful remediation program, there exists no practical and detailed standardised framework for postgraduate medical remediation.

Aims: This paper seeks to analyse current postgraduate remediation programs in peer-reviewed literature to facilitate the creation of a standardised and effective remediation framework. This can be applied in palliative medicine education to ensure comprehensive and efficient training.

Methods: This systematic review on postgraduate medical remediation programs utilised Krishna's Systematic Evidence Based Approach (SEBA). As part of SEBA, independent use of Braun and Clarke's approach to thematic analysis and directed content analysis identified main themes in medical student portfolios.

Results: The search retrieved 3923 abstracts, with 289 full-text articles reviewed and 111 articles included. Comparison of the categories and themes identified from the Split Approach were similar and included the goals of remediation, identification of individuals in need of remediation, content, approaches, modalities, enablers and barriers.

Conclusion: The lack of standardisation in remediation processes across the board may hamper the effectiveness of programs and thus justifies the need for a more comprehensive review of postgraduate remediation in medicine. Host organisations should work together with doctors to ensure vertically and horizontally integrated remediation programs that will allow for the development of a more clinically and ethically competent palliative care workforce.

Abstract number: E-15
Abstract type: Poster

The Online Representation of Palliative Care by Practice, Policy and Advocacy Organizations: Definitional Variations and Discursive Tensions

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Background: Evidence suggests that negative beliefs and a lack of clarity surrounding the meaning of palliative care persist as potential obstacles for those in need of palliative care. The information that is available to the public possibly contributes to this.

Aims: To examine the representations of palliative care within the online information spread by palliative care policy, advocacy and practice organizations in Flanders, Belgium, to detect elements of congruence, ambivalence and tension within and between these representations and to identify and interpret the discourses at play.

Methods: A discourse-theoretical analysis of publicly available information was conducted. An inventory of relevant organizations was made and through the purposive sampling technique of maximum variation their websites were explored in cycles of seven organizations until theoretical saturation. In total information from 56 organizations was analyzed.

Results: Discrepancies were found in the way palliative care was defined in relation to curative, end-of-life, terminal and supportive care. Yet, beyond these definitional variations, meaning was also generated through the representation of palliative care as a culture, connected to the practice of 'total care', the values of compassion and openness and the positioning of the "palliative patient" as firmly embedded within a social context. Tensions arose around the concepts of autonomy, a natural death and an emphasis on the quality of life away from death and dying.

Conclusion: Discursive tensions and definitional variations in the representations of palliative care suggest that the online information of palliative care can be seen as a potential source of confusion for the public. This analysis provides insights that may help to improve clarity towards the public.

Abstract number: E-17
Abstract type: Poster

Perceived Palliative Care Educational Needs: A Qualitative Study of General Practitioner (GP) Trainees in Ireland

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Background: It is estimated the prevalence of palliative care need in Ireland will almost double in the next 30 years. Primary care physicians, such as GPs, play a central role in the delivery of palliative care worldwide. Training doctors to become proficient in this area requires a robust post-graduate palliative care education programme. While there is evidence to support the value of participatory approaches in ensuring the success of education and training programmes, there is a lack of research identifying GP trainees' educational needs.

Aims: To explore the perceived palliative care educational needs of GP trainees; To determine GP trainees' preferred educational methods.

Methods: Qualitative design was undertaken using focus group interviews. Six groups were facilitated with 59 participants (38 female, 21 male), 3rd and 4th year GP trainees, working in general practices. Semi-structured interviews were performed, audio-recorded and transcribed. The data analysis method was Reflexive Thematic Analysis (Braun and Clarke 2006, 2020) using their 6 phases framework which adopts an inductive approach to systematic coding to identify themes.

Results: Trainees identified 7 core areas of educational need including addressing emotions evoked, enhancing communication skills, ethical considerations, managing complexity, providing palliative care in the community, role of the palliative care team and enabling trainees by further understanding palliative care. Trainees expressed a wish to receive training by access to resources, didactic teaching, practice of communication skills, experiential learning and practical matters. Fear of palliative care provision was expressed in all groups (21 references) and identified as a barrier to care.

Conclusion: Our findings indicate that GP trainees are challenged by complex aspects of palliative care. Development of further training should focus on bespoke content and educational strategies that meet their identified educational needs.

Abstract number: E-18
Abstract type: Poster

Development of an Early Career Research Committee and Online Mentorship Programme as part of the mySupport Study

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Aims or goal of the work: The primary aim was to create an international network of early career researchers (ECRs) who are working as part of the mySupport study team. The Early Career Researchers' Committee (ECRC) was developed to encourage shared learning between ECRs across six international project sites. A secondary aim of this work was to foster collaborations between the ECRC and the wider mySupport consortium members via an online mentoring system.

Design, methods and approach taken: The development of this committee and mentorship programme began with a needs analysis through an online focus group. The ECRC online platform was developed through Microsoft Teams, which included documentation and activity channels, as well as group chat and video call facilities.

Results: During the needs analysis the members explored group expectations and actively engaged in the development of their own committee and programme. A core committee was established, with a decision to alternate the roles and responsibilities of its members every six months. Role alternation encouraged capacity building and development of leadership skills. The committee has monthly virtual meetings and presentation which facilitate knowledge exchange between its members. A secondary outcome of this committee was the development of a mentorship programme. The ECRC mentorship programme included an establishment, progression and evaluation phase. Online resources were provided to each mentor/mentee group to ensure that set action points were achieved for each phase. The mentorship programme was approved for a digital badge accreditation. Receiving a digital badges accreditation will highlight the ECRC achievements to both national and international employers.

Conclusion/lessons learned: The ECR committee and mentorship programme recognises and nurtures career progression and career goals. In order to be truly successful, early career researchers need to be actively involved in this process.

Abstract number: E-19
Abstract type: Poster

Palliative Care Knowledge and Attitudes towards Caring for Terminally Ill Patients among Nurses: What Are the Factors Associated with Positive Attitudes and Better Knowledge?

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Background: Good nursing care is a core component in providing high quality care for terminally ill patients. Inadequate palliative care

knowledge may contribute towards negative attitudes in the care of dying patients.
Aims: The study aimed to examine the level of palliative care knowledge among nurses, their attitudes towards caring for patients at the end-of-life and to identify factors associated with positive attitudes and better knowledge.
Methods: 240 nurses from a tertiary private hospital in Malaysia completed the validated Palliative Care Quiz for Nursing (PCQN) and the Frommelt Attitudes Toward Care of the Dying (FATCOD) Scale questionnaires. All responses were analyzed using descriptive statistics, and associations between participant factors with PCQN and FATCOD scores were further examined using multivariate logistic regression.
Results: The level of palliative care knowledge among nurses was poor, with a median score of 9 out of 20 (45%) (interquartile range: 3). However, the attitudes towards caring for terminally ill patients were positive, with a median score of 106 out of 150 (70.6%) (interquartile range: 13). No correlation was found between PCQN and FATCOD scores. Participants who had attended palliative care training had significantly higher FATCOD scores (OR 3.02; 95% CI 1.61-5.63, p=0.001). No significant association was found between PCQN score and participant gender, age, education level, years of nursing experience and previous palliative care education.
Conclusion: Although the level of palliative care knowledge was poor among nurses, positive attitudes towards caring for patients at the end-of-life were observed. Participation in palliative care education significantly contributed to better attitudes towards managing dying patients, highlighting the importance of targeted palliative care education to improve level of palliative care knowledge, attitudes and quality of nursing care.

Abstract number: E-21
Abstract type: Poster

Future Competence Needs in Palliative Care

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Background: Globally, the need for palliative care is increasing due to ageing population and the increased number of non-communicable diseases. Palliative care is one of the priorities in the development of integrated, people-centred health services. Therefore, there is an increasing need for physicians, nurses and other health care professionals with adequate palliative care competencies in different contexts.
Aims: The aim of this study was to describe the future competence needs within palliative care, from the perspectives of both physicians and registered nurses.
Methods: The study was a descriptive qualitative research design. The data were collected from a convenience sample of Finnish physicians and registered nurses by the means of an electronic survey containing close-ended and open-ended questions. In this study, physicians' and registered nurses' answers to one open-ended question concerning their perceptions of future competence needs in the palliative care in the next decade were examined. An inductive content analysis was used to analyse responses.
Results: The main future competence needs in palliative care for the next decade were categorized into

1) Palliative care competence at all levels within healthcare and social welfare services;
2) Individualized palliative care competence;
3) Person-centred encounter competence; and
4) Systematic competence development in palliative care.

Conclusion: In the future, palliative care competence is needed at all levels of palliative care, and more increasingly within the outpatient and home environments regardless where patients live. Health care professionals' openness to new challenges and continuous competence development have an impact on the quality of palliative care. Inter-professional education would clarify palliative care professionals' roles and promote efficient team collaboration benefiting both patients and families.

Abstract number: E-22
Abstract type: Poster

Professional's Expectations and Preparedness to Implement Knowledge-based Palliative Care at Nursing Homes before an Education Intervention

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Background: Today it is only the most frail older persons in the Swedish society that are living in nursing homes, which is a major arena for the provision of palliative care. Previous research has identified knowledge gaps among the professionals who do not have sufficient training in managing symptoms and other aspects of palliative care. A critical factor for successful implementation is organizational readiness for change which includes the professional's experiences and expectations.
Aims: To explore the professional's expectations and preparedness to implement knowledge-based palliative care at nursing homes before an educational intervention.
Methods: This study is a part of the project "Implementation of Knowledge-based Palliative Care" (KUPA) through an educational intervention for the professionals. In this study was focus group interviews performed including total 48 professionals of mixed professions from six nursing homes. The interviews were performed before the educational intervention started. The data has been analyzing using qualitative content analysis with an inductive approach.
Results: The result included one theme; *hopeful but doubts about the organization's readiness*, and five main categories; *increased knowledge, consensus in the team, vision of the future, trust in leadership* and *insufficient resources and steering*. The participants rise palliative care as an important part of their work and they have hopefulness that the education can have a better outcome. However, the professional shows skepticism concerning the organization's readiness to implement palliative care in the daily work after the education.
Conclusion/discussion: The finding expressed ambivalence by two contrasting dimensions hopefulness and doubts of the organization's readiness for change. There is a need for identifying the professionals' credence to the organization before implementation to overcome possible obstacle.
Funding: The Swedish Research Council.

Abstract number: E-23
Abstract type: Poster

A Community-based Training Program for Health Care Professionals on Primary Pediatric Palliative Care

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Introduction: Pediatric Palliative Care aims to prevent, identify and treat suffering in children with life-threatening illness and their families. In the Philippines, provision of palliative care services is emphasized in the Universal Health Care Law. With the increasing number of children needing palliative care, equipping healthcare professionals with the

knowledge and skills on palliative care is essential. This paper aims to develop a Community-Based Training Program for healthcare professionals on primary pediatric palliative care.
Method: The community-based program is built on an Outcome-Based Education framework. Review of related literature and analysis of the learning context were done. A competency analysis (task analysis and competency table) was done to generate educational goals, intended learning outcome and formation of content outline. The instructional and assessment strategies were determined accordingly.
Results: Healthcare professionals need to be equipped to carry out palliative care services in the communities. The competency analysis yielded seven educational goals that involved cognitive, affective and psychomotor domains. Some of the instructional strategies determined were values clarification and mentoring, lectures, role playing, role modeling and patient encounters. The assessment strategies included, pen and paper test, feedback on role playing and case presentation, reflection paper, journal and portfolio.
Conclusion: The Community-based Training Program emphasized the need for a collaborative effort among healthcare professionals and educators to derive appropriate goals and strategies to ensure the development of skills, knowledge and attitude among the participants on Palliative Care. With its conception, healthcare professionals can become primary pediatric palliative care providers that could aid in delivering the services to more children and in establishing timely referral to the specialists.

Abstract number: E-24
Abstract type: Poster

The Sound of Anxiety: Exploring the Effect of Audio Recordings of Breathing on Self-reported Breathlessness

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Background: Breathlessness is common, distressing and can be associated with anxiety. Inducing breathlessness activates areas of the brain relating to fear, and viewing images or videos of breathlessness can elicit breathlessness.
Aims: We aimed to investigate the effect of audio recordings of breathlessness on self-reported breathlessness. We hypothesised that listening to the recordings would elicit breathlessness, and that different aetiologies of breathlessness might modulate this effect.
Methods: Live experiment with members of the public aged 16 and above at the 'on edge' exhibition (Science Gallery, King's College London 2019). Participants listened to audio recordings of breathlessness caused by 1) exercise, 2) anxiety, 3) chronic lung disease and 4) at the end of life, in a random order. They were asked to identify the cause of breathlessness and report how breathless they felt (before and after recordings) using a validated 0-10 numerical rating scale (NRS).
Results: 268 participants, 63% female, 67% aged 18-35 years old. Cause of breathlessness was correctly identified as anxiety (by 69%), lung disease (39%), end of life (33%), and exercise (59%). Participants' self-reported breathlessness increased after each recording: mean NRS score 1.29/10 at baseline, 1.42 after 1 recording, 1.50 after 2, 1.51 after 3, and 1.56 after 4. Self-reported breathlessness was highest for anxiety.
Conclusions: Listening to audio recordings of breathlessness increases self-reported breathlessness. Therefore those caring (formal and informal) for someone who is breathless may be more likely to experience breathlessness; the clinical implications of this should be explored. Causes of breathlessness, particularly anxiety & exercise are identifiable from audio.
Funding: Science Gallery London

Abstract number: E-25
Abstract type: Poster

Palliative Care in 2020 & Beyond Workshop: A Platform to Develop Palliative Care Advocacy in Turkey

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Background: Universal health Coverage, and the World Health Assembly, require palliative care (PC) as a core component of health services. In the WHO atlas 2020, Turkey progressed from capacity-building (Category 2) to isolated PC provision (Category 3a). Co-ordinated, strategic actions are needed to achieve Category 4, i.e. integrated & comprehensive PC in Turkey.
Aim: A national multi-stakeholder workshop aimed to increase widen understanding of the role and potential for PC in cancer & to develop strategic strategies for implementation.
Methods: The workshop was attended by 80 healthcare professionals, civil servants, and international PC experts. Training (research evidence and clinical practice) and working group sessions were held to determine the current status, shortcomings and specify solutions for future PC in cancer in Turkey beyond 2020.
Results: Positive developments in PC after 2010 were acknowledged. PC services were mostly available in major cities. PC centers embedded in oncology & general hospitals were run mostly by anesthesiologists & oncologists. The latest regulations and Pallia-Turk project provide frameworks to develop nationwide PC activism. The barriers to progress are: limited PC training, lack of integration into cancer care, public's lack of PC awareness, and legislative issues to DNR orders. The contextual suggestions by participants are:

1) all healthcare workers must acquire a minimum knowledge & skills in PC.
2) Home-based PC should be timely & responsive, coordination among patient's care stakeholders.
3) Hospital-based PC for intensive symptom control or reduce caregiver burden.
4) integrating PC into cancer care to avoid late referral.
5) legal arrangements for DNR orders.
6) Public awareness via mass media initiatives.

Conclusion: A national strategy co-developed by multi-level stakeholders enabled a set of auditable actions to progress towards an integrated and comprehensive PC. This will be appraised and refined annually.

Abstract number: E-26
Abstract type: Poster

Portfolio Use in Teaching and Assessing Communications, Ethics and Professionalism: A Systematic Scoping Review

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With accounts of unprofessional conduct often linked to unethical practice and poor communication, there is growing recognition that training in communication, ethics and professionalism (CEP) should be carried out in tandem. The importance of CEP is all the more pronounced in palliative care where physicians require these skills to address the complexities in end-of-life care. The longitudinal nature of CEP training begs the need for a scaffold that gives space for individuals and concurrent purposeful support to allow for refinement of attitudes. The use of portfolios in teaching and assessment of CEP in undergraduate and postgraduate medical education programs is thus proposed. A Systematic Evidenced Based Approach (SEBA) guided Systematic Scoping Review (SSR) (SSR in SEBA) was employed. A total of 12,313 abstracts were reviewed, 721 full text articles were evaluated, and 81 articles were included and analysed. Two themes were identified: 1) Reasons for use of portfolios to teach and assess CEP, and 2) Use of portfolios to teach and assess CEP. This SSR in SEBA evidences the mutually reliant nature of communication, ethics and professional development and their combined roles in nurturing professional identity formation (PIF) that should begin as early as medical school. CEP and PIF's reliance upon interlinked milestones underline the need for regular holistic assessments of the individual and contextual factors affecting one's ability to achieve milestones. Assessing and verifying achieved milestones or micro-competencies can be personalized, scrutinized, reflected upon in a portfolio and then later re-evaluated to accommodate evolvements in the development of the student. The success of a framework to operationalize CEP portfolios however have logistical requirements: mentor and user training and importantly their receptiveness influenced by guarantee of confidentiality and accessibility, consistent framework and objectives and multi-source assessments.

Abstract number: E-27
Abstract type: Poster

The Development of a Palliative Care Journal Club to Improve Clinical Care in a Hospice through Evidence-based Practice

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Background: Many palliative care organisations use journal clubs to support educational development for staff. However, to date, the potential to use journal clubs to directly improve clinical care in hospices (through quality improvement activity) has not been described in the literature.
Aims: We describe the development of a multidisciplinary hospice journal club, through which aimed to (1) develop research questions to clinical care problems in the hospice and (2) identify solutions to these problems to improve care delivery.
Methods: In January 2019, we established fortnightly journal club meetings, which provided staff with the opportunity to present hospice-relevant palliative care research. In these meetings, we discussed the main findings, clinical practice implications and future research questions. Initially, the meetings were in-person, but we later hosted these online (via Microsoft Teams) due to the Covid19 pandemic, which enabled virtual participation. We used the research questions generated to inform future quality improvement work. We asked staff to complete a feedback survey to determine their views of the process.
Results: We have conducted 30 journal club meetings, which have generated 124 research questions. Thirteen meetings were virtual. We have conducted quality improvement work using these research questions to improve clinical care. Nineteen staff (representing 5 clinical sites) completed feedback. The feedback was positive, with participants stating that the journal club was educational, clinically relevant and enjoyable. The main problem identified by participants were technological issues relating to participating in the virtual meetings.
Conclusion / Discussion: We have demonstrated how a palliative care journal club can be used to improve clinical care in a hospice. Our experience can be used by other palliative care settings to engage staff in research and improve care for those with serious illness.

Abstract number: E-28
Abstract type: Poster

Palliative Care Competence of Advanced Nurse Practitioner Students

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Background: In Finland, the development of palliative care education has been one of the national priorities. EduPal- project started in 2018, and its goal is to increase quality of palliative care by developing education for professionals working in palliative care. In the new master education, the aim is to prepare master students to work in the specialist level of palliative care. To track their development an assessment of their palliative care competence is necessary.
Aim: To evaluate students' palliative care competencies prior and after completion of palliative care module of the master's degree program.
Methods: Cross-sectional comparative design was used. Students (n=36) palliative care competence was evaluated with a knowledge test develop by the ELNEC consortium (ELNEC-KAT), with a self-assessment tool of palliative care competence (NCPC) by Slåtten, and advanced practice nurses' core competence in palliative care (APN-CCPC) tool developed for the study. The post data collection will end by March 2021.
Results: In overall, the students' palliative competence was in the beginning of the education relatively good, both in a knowledge test and in their self-evaluation. However, there was significant variation between the individual students. Students were more critical in their assessment of advance practice core competence. The results of the post evaluation and comparison between the pre- and post-evaluation will be provided in the conference presentation.
Conclusions: The evaluation in the beginning and the end of education with the same instruments provides possibilities to track potential development of palliative care competences. It may support students learning by helping to identify areas in need for developing. The heterogeneity in the student population regarding their background and level of competences in the beginning of the education is a challenge for the educators.

Abstract number: E-30
Abstract type: Poster

An Interprofessional Training Program for Mediators and Palliative Care Hospital Professionals: A Pilot Study and its Evaluation

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Background: Oncological culturally and linguistically diverse (CALD) patients represent a vulnerable population with high risk of lower quality care. Many difficulties have already been described during mediation. Better interaction with CALD patients is a challenging competence for a Specialized Palliative Care service (SPCS).
Aims: The primary aim is to develop an inter-professional training program in difficult communication for mediators and a SPCS; the secondary aim is to increase palliative communication's mediators' competences and SPCS' intercultural competences.
Methods: We piloted and evaluated a mix method before/after training program. The components of the mutual training program were:

- "Team-based learning" methodology"
- role-play
- clinical practice in medical consultations (MC).

Participants were 8 mediators from 4 different ethnic groups (Ukrainian-Moldavian-Georgian-Romanian, Arab-North African, Albanian, and Ghanaian-Nigerian), 3 doctors and 3 nurses of SPCS. Data were collected and analyzed by portfolios, qualitative interviews, ethnographic analysis, and participants' field notes of the MC.
Results: Preliminary data suggest, from the mediator point of view, to understand the MC' objectives and words. From SPCS point of view, to understand the cultural differences in the CALD patients. All participants expressed the need of briefing and de-briefing before and after the MC. Further results will be presented at the congress.
Conclusion: We piloted a new training program that could improve collaboration between mediators and SPCS and improve CALD patients' care.

Abstract number: E-32
Abstract type: Poster

Training of Palliative Team Professionals in Portugal. Cross-sectional Descriptive Study

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Background: Palliative Care (PC) training is crucial for good practice. In Portugal, we little known about specific PC training of professionals working in PC. In a 2017 study, we characterized the training profile of these professionals and repeated the study in 2019 to understand the evolution and make an analysis of training needs in the country.
Aims: To characterize the PC training of professionals within the PC teams in Portugal and analyze their evolution 2017-2019.
Methods: Descriptive, observational and cross-sectional study. In 2019 we sent a form to 80 portuguese PC teams. Descriptive analysis was used to analyzed the variables: typology and level of training. We compared 2017 and 2019 results.
Results: Data from 664 professionals of PC seetings were used: 308 Inpatient Unit (IU); 198 Hospital Support Teams (HST); 198 Home Care Teams (HCT); 30 Pediatric Hospital Support Teams (PdHST).
Training typology - IU; HST and HCT, post-graduation is the main one, 101(32.8%); 76(38.4%) and 69(34.8%), respectively. Basic training predominate in PdHST 7(23,3%). 84 professionals from IU (27.3%) and 16 from PdHST (53.3%) have no PC training. Post-graduation is predominant for physicians 55(43%) and nurses 120(34.3%). In other professional areas, only basic training appears.
Training levels - 205(30.9%) basic training, level A; 169(25.5%) level B; 149(22.4%) level C; 141(21.2%) professionals did not answer or have no training. Team coordinators (104) only 58(55.8%) have level C.
Discussion: Training at the IU has improved- 2017 basic training predominated, in 2019 it is postgraduate ($\rho>0.05$). However, increased the% of professionals without training at the IU [2017-20.6% vs 2019-27.3%, $\rho=0.032$] and at HCT [2017-3.3%; 2019-10.1%, $\rho=0.006$]. In 2019, there was an increase of professionals with level B (12.4% vs 32.3%, $\rho<0.001$) and a decrease with level C (39.5% vs 28.5%, $\rho<0.001$).
The need for advanced training of professionals working/coordinating PC teams persists.

Abstract number: E-33
Abstract type: Poster

Nurses Perspectives about Existential Issues in Neurological Care

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Background: Existential issues are essential in the care with neurologically ill people, but there is a lack of research examining how nurses meet this patient group and their families in existential issues.
Aims: The aims of this study were to explore reflections among nurses at neurological wards before and after training in discussing existential issues and to examine their experiences of an education programme.
Methods: Nurses in inpatient and outpatient care at a neurological clinic in Sweden participated in an education programme to facilitate talking about existential issues related to patients with neurological diseases and their families. Data were collected from focus group interviews and were analyzed by qualitative content analysis.
Results: Working with neurological ill people was experienced as difficult. Many diagnoses are progressive and the nurses often followed the patients during the illness trajectory. They described that existential issues generally had a low priority with lack of time for reflections. Both before and after the programme, they mentioned internal and external hinders to perform the conversations. After the programme, they emphasized being more comfortable talking about existential issues and how to manage these conversations. They became more confident in asking about existential issues, meeting questions without answers, and staying with the person in the difficulty.
Conclusion: Neurological diseases are often progressive and sometimes lethal which raises existential issues. It might be relevant to introduce a palliative approach earlier on in patients' trajectories to meet the patients' needs. The knowledge that internal and external hinders aggravate the conversations should compels the organization to work to improve these conditions and education in existential issues should be given.

Abstract number: E-35
Abstract type: Poster

Perceptions of University Students from Different Disciplines: Starting the Social Debate in Palliative Care

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Background: University students are the future professionals who will influence society. It is thus essential to improve students' understanding of palliative care (PC), especially those in the non-health field, to generate and encourage propitious opinions about PC. This study describes the perception of PC among university students from different disciplines.

Method: Qualitative exploratory study using virtual focus groups (FGs) and design thinking (DT) tools. To understand the perceptions about PC, Spanish university students from various disciplines were invited to participate in video-recorded FGs. Three FGs were transcribed verbatim and analysed thematically. An additional fourth FG was held to present and validate the preliminary results. Numerous researchers (medicine, nursing, social work, communication, linguistics) were involved in the discussion of the final thematic analysis.

Results: Twenty students (mean 19 years old), participated in the initial FGs and six in the final one: nine were from health and 11 from non-health disciplines. Four themes and seven sub-themes were found: i) Students have a varying understanding about palliative care; ii) Students see PC as an important and necessary field; iii) Students build counter-narratives against PC myths, demonstrating that PC brings key benefits into people's lives; iv) Students believe that PC is not a daily issue among their peers. Finally, a common speech frame among students exists: palliative care is a synonym of death.

Conclusion: Despite the fact that students do not know much about PC, the topic easily arouses their interest. When they approach it as a group, it promotes reflection and positive discussion. Universities are privileged places to stimulate the humanity of students towards those who suffer intensely from serious illness. Students from different disciplines could be the target of innovative educational initiatives on PC.

Abstract number: E-36
Abstract type: Poster

CoViDPACT: The Development, Delivery and Evaluation of a Socially Distanced Course to Improve Confidence of Clinical Staff Communicating Bad News by Telephone during the COVID-19 Pandemic

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Introduction: The COVID-19 pandemic increased the volume of critically ill patients in hospital. Healthcare professionals (HCPs), many of whom had limited experience of communicating bad news to relatives, needed to be able to do this and often by telephone.

Aim: To design, deliver and evaluate a simulation based course to help HCPs communicate about death and dying by telephone during the pandemic.

Methods: In March 2020 a multi-professional group of clinicians and educators developed a 2-hour, socially distanced communication skills course for HCPs in our Trust. Courses ran through March-June 2020, each course facilitated by 3-5 faculty.

The course taught the 'SPIKES' structure for breaking bad news (BBN), using it to critique a pre-recorded conversation and role play of simulated scenarios, with faculty feedback.

Participant confidence (using 1-5 scale) was assessed by pre and post course questionnaire, and analysed by descriptive statistics. Qualitative feedback was from participant questionnaires and thematic analysis of a faculty focus group.

Ethical approval was gained.

Results: 79 HCPs attended a course; 55 gave feedback: nurses (24), doctors (21), allied health professionals (10).

There was significant improvement in participant confidence in having a communication structure for BBN (mean change 1.69 (CI 1.94,1.44), p=0.03); applying SPIKES to BBN by telephone (mean change 1.82 (CI 2.05,1.59), p=0.005); giving and seeking feedback to improve communication (mean change 1.55 (CI 1.79,1.3), p=0.012).

Qualitative data indicated excellent engagement and relevance beyond the pandemic. A faculty focus group identified key themes: applicability post COVID-19, greater openness to communication challenges, and awareness of emotionality in practice.

Conclusion: An innovative course developed during the COVID-19 pandemic demonstrated improved HCP confidence in communicating bad news. Skills taught are applicable post pandemic and will inform further course development.

Abstract number: E-37
Abstract type: Poster

Using Death Cafés as a Method for Discussing Death and Dying with 3rd Year Student Nurses: A Qualitative Study

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Background: Death Cafés are increasingly being held to facilitate discussions about death and dying among the general public. They provide a safe, confidential space to share sensitive conversations about death and dying. However, death cafes have not been used in higher education to teach nursing students about death and dying.

Aim: To explore nursing students' experience of participating in a death café and their learning about death and dying.

Methodology: A qualitative design using face to face semi-structured interviews with 3rd year nursing students who had participated in death café session at a university, facilitated by an external accredited facilitator. Purposive sampling was employed to recruit five nursing students who shared their experiences. Data were thematically analysed. Ethics approval was obtained from the University training the nursing students.

Findings: Students viewed Death cafés as informative, a positive way of learning about a sensitive topic, and stimulating debate while providing a safe environment to discuss elements of death and dying. Five themes were extracted; Anticipations of the death cafés, Timing of death cafés within the curriculum, Facilitation, Trust within the group, and Reflection on practice.

Conclusion: Teaching students about death and dying using death Cafes can provide a safe environment for learning such a difficult topic. Facilitation is critical to the self-scrutiny by students, and the death café session achieved this. This, being a very small study revealed students' thoughts about death and dying. Future study is recommended to include 1st, 2nd and 3rd year students.

Discussion/ implications: It is expected that students may feel vulnerable, but it is important that vulnerability be translated into strength enabling openness and reciprocal sharing of inner thoughts and feelings about death and dying. External facilitators may be better received by students as they are neutral and may enable self-disclosure.

Abstract number: E-38
Abstract type: Poster

Towards Effective Study of Mentoring: The Seba Guided Systematic Scoping Review

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Background: Systematic scoping reviews are a relatively new method of knowledge syntheses that have gained prominence in the field of medical education. Our study evaluates systematic scoping review (SSR) use in Internal Medicine (IM) due to the abundance of prior studies, allowing conclusions to be drawn in parallel to its subspecialty, palliative medicine (PM). PM in particular stands to benefit from our proposed approach, especially with how COVID-19 has forced a change in mentoring structures. It is imperative that the tools used to evaluate mentoring are dynamic and holistic in such turbulent times.
Aims: To highlight its features and suitability for the effective study of mentoring, we demonstrate Krishna's Systematic Evidence Based Approach (SEBA) to determine what is known of SSR use in IM.
Methods: One team of researchers employed Braun and Clarke's approach to thematic analysis to independently review the articles identified from five bibliographic databases and seven medical education journals on the use of systematic scoping reviews in medical education. A second team of researchers employed Hsieh and Shannon's directed content analysis for concurrent analysis. A third team summarised the included articles.
Results: The results of this 'Split Approach' were compared. 3134 abstracts were identified and 62 articles were analysed. Four themes were ascertained from thematic analysis, and one additional category from directed content analysis. These were: characteristics, methodological framework, indications and limitations, use of grey literature, and the structure of systematic scoping reviews.
Conclusion: In this paper, we show that the SEBA is more than equipped to fill in the gaps of SSRs in IM education and its subspecialty teachings to allow for its holistic appreciation. In advancing this approach, we also proffer a new tool to assess the quality of grey literature and ensure a balanced perspective in the evaluation of mentoring in PM.

Abstract number: E-39
Abstract type: Poster

Impact of Using of a Tool to Stimulate Reflection about End-of-Life Communication in a Competence-building Initiative in Swedish Elder Care

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Background: Residential care homes (RCHs) are increasingly providers of end-of-life (EOL) care, with staff playing a central role in communication about matters related to dying and death. While residents are generally positive to opportunities to discuss thoughts, preferences, and concerns related to the EOL, such conversations remain rare in practice. Means to support staff engagement in EOL conversations are therefore needed.
Aim: The aim was to explore impact of the use of a conversation tool, the DöBra cards, during a competence-building initiative comprising workshop series promoting EOL communication.
Methods: Series of 4 consecutive workshops were conducted with 5 groups of 38 staff from 6 Swedish elder care services as part of a participatory action project. Workshops integrated individual and joint reflection using the DöBra cards, a Swedish translation and adaptation of the English-language GoWish cards. The cards consist of 37 statements covering physical, practical, social, and existential EOL matters, with group discussions. A longitudinal qualitative approach for analyzing workshop transcripts was used.
Results: Reflective exercises enabled staff to approach their own mortality and expand their frames of reference, by shifting perspectives of EOL care and communication. The use of the DöBra cards was seen to have an impact both on a personal level, e.g. through cognitive and/or emotional engagement with EOL-related matters, and interpersonal level, through triggering discussions that encouraged critical reflection about previous experiences and knowledge exchange between participants.
Conclusion: The DöBra cards were found to be an appropriate and user-friendly tool to stimulate reflection. Our study suggests that use of the cards impacted staff EOL competence-building in several ways. By integrating processes of introspection and extrospection, reflective exercises can help create conditions conducive to change and learning about EOL communication.

Abstract number: E-40
Abstract type: Poster

How to Explain Resilience and its Importance: A Short Educational Course Using Examples from Science Fiction and Real Life

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Background and aim: Resilience is a major skill for professionals in palliative care. Several definitions of "resilience" exist, most of which build upon a sense of coherence (comprehensibility, manageability, meaningfulness). Teaching this skill is important but difficult due to its abstract nature. The aim of this paper is to describe a short single session educational course that uses the main character traits of resilient iconic fictional and non-fictional people as examples, thereby increasing the interactivity and effectiveness of the course.
Methods and approach: After a literature review the following course structure was created. First, the definition of the concept of resilience and its challenges in daily practice are explained. Second, three resilient characters are presented, including their most iconic quotations. These include a 20th-century long-distance runner (endurance and persistence: manageability); two fictional characters from the Star Trek universe, a Klingon warrior (honour and acceptance of destiny: meaningfulness) and a Vulcan science officer (logic: comprehensibility). Participants then vote on which characters best describes their resilience style.
Third, resilience-enhancing interventions (institutional, team, individual) are briefly described and the results of the vote are then discussed interactively. Oral feedback from the course participants (medical students, physicians, nurses) was positive.
Conclusion/ lessons learned: Using fictional or non-fictional iconic characters as examples of resilience is a creative way to increase interactivity in a single educational course.

Abstract number: E-41
Abstract type: Poster

A Systematic Scoping Review of Undergraduate Ethics Education Programs from 1990 to 2019

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Introduction: End-of-life care has increasingly complex moral and ethical issues, growing sociocultural influences, evolving legal standards of practice, public expectations, and financial concerns. A medical ethics curriculum could enhance ethical reasoning skills and adequately prepare palliative care physicians, nurses, and allied health professionals for these challenges. Acknowledging the need to instil basic and consistent ethics knowledge and portable skills across different circumstantial settings, a better understanding of how medical ethics is taught and assessed is required.
Methods: Krishna's Systematic Evidenced Based Approach (SEBA) was employed to study diverse socio-culturally informed aspects of different ethics education approaches across different undergraduate medical curricula. Two systematic scoping reviews (SSRs) on the teaching and assessment of ethics were conducted.
Results: 79 articles on teaching and 51 articles on assessment methods were included. Themes from both SSRs include:

a) teaching modalities and objectives,
b) curriculum topics,
c) enablers and barriers to teaching ethics effectively,
d) assessment modalities and objectives and
e) pros and cons of each assessment method.

Discussion: Successful medical ethics curricula broaden students' perceptions, enhance theoretical and procedural knowledge, refine practical skills, and transform professional behaviour. The same can be done for postgraduate education in palliative medicine, where end-of-life professionals could be taught and assessed on ethics in a stage-wise manner to optimise learning.
Conclusion: This study confirms the need for a longitudinal and multi-stakeholder approach to ethics training and assessment, with due consideration for the palliative care practitioner's professional development, organisational delivery, and positive patient outcomes. Further design of multidimensional and robust tools should be explored, considering the formal, informal, and hidden curriculum.

Abstract number: E-42
Abstract type: Poster

'The Resus Doll Is Dead, What Now?' End-of-Life Care Teaching and Simulation: A Literature Review

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Background: Simulation & high-fidelity simulation involves using manikins, clinical training suites, wards, computer programs and theatres in medical teaching. These teaching formats have established themselves in medical undergraduate and postgraduate education. Rated highly among students, they have also been shown to be effective learning tools.
Aims: To reduce the potential risk to patients and their proxy associated with learning 'at the bedside', which can pose a challenge in medical and in particular palliative settings. Education and training methods that do not expose patients to preventable communication blunders from less experienced practitioners are a priority. Simulation and high-fidelity simulation provides a way for students and doctors to train safely, before entering real-life scenarios.
Methods: We provide a summary review on the current literature and evidence for simulation and high-fidelity simulation in palliative and end-of-life care settings, and discuss potential uses of technologies including virtual and augmented reality in future training.
Results: The most common form of simulation in palliative medicine is often an actor-based role-play scenario with particular emphasis on communication skills. This is expensive and time-consuming to set up. Less evidence was found on the use of high-fidelity simulation in end-of-life care teaching.
Conclusion: Palliative medicine has been slow to adapt to an educational method and environment that now is widely used across other areas of healthcare. There has been less emphasis on training with manikins and even less on using computer simulation and virtual reality environments to recreate challenging end-of-life care scenarios. We provide some examples of where this could benefit the curriculum.

Abstract number: E-43
Abstract type: Poster

Using Technology to Help Combat COVID-19

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At the start of the pandemic there was a clear need to prepare and equip care settings with the knowledge, skillsets and in some cases the technology to allow patients to say "goodbye" to their loved ones and reduce feelings of social isolation.
'How hospitals, hospices & care facilities can use Skype to reduce loneliness during the Coronavirus (COVID-19) pandemic' was written by James Norris, peer reviewed by Professor Mark Taubert and published on 15th March 2020.
Results: The tutorial received a positive response from care professionals and was listed as a resource in the European Association for Palliative Care (EAPC)'s Coronavirus and the palliative care response and The International Association for Hospice and Palliative Care (IAHPC)'s 'Resources relevant to Palliative Care and COVID-19'.
The article helped to spark conversations around the importance of saying 'goodbye' virtually when goodbyes cannot take place in person. A campaign called 'Tablets Against Loneliness' was launched to expand upon this area . The campaign's mission was to raise awareness at the start of the pandemic about using video calling technologies, sharing a basic framework and provided technical support for care settings when using video calling technologies.
Social distancing guidelines meant that many funerals took place with a small number of attendees and some funerals in the UK were postponed. A framework for funeral directors and funeral director associations was then launched by the Digital Legacy Association. It argues that funeral director associations should include virtual funeral conversations as part of their duty of care when social distancing measures are in place... No funeral director associations in the UK have adopted the framework or developed their own.
Conclusion / lessons learned: A BMJ tutorial acted as a snowball for advocacy, change and collaboration. More work, advocacy and campaigning is required.

Abstract number: E-45
Abstract type: Poster

The Effect of Two Hour Palliative Care Educational Course on Doctors' and Nurses' Knowledge, Practices and Difficulties in Palliative Care in General Hospital Celje

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Background: Validated tools for knowledge, self-reported practices and difficulties in palliative care (PC) have been developed but have not been adapted for Slovenian environment yet.
Aims: To study the effect of PC educational course on knowledge, practices and difficulties in PC.
Methods: Doctors and nurses of General hospital Celje voluntarily participating in an educational course of PC were included. Literature was searched for validated tools testing knowledge, self-reported practices and difficulties in PC. Baseline state was evaluated. Two weeks after a two-hour educational course re-evaluation using the same tools was performed and the results were compared.
Results: The PC knowledge test, The PC self-reported practices scale and PC difficulties scale were selected. Validated translation from English to Slovene was performed and tested in a pilot study. At baseline 103 and at re-evaluation 42 health workers participated. PC knowledge was 67 ± 16 % at baseline. The results were better in doctors, younger age, less years of service, more experience with PC patients and with previous education in PC. At re-evaluation the PC knowledge increased by 5 ± 12 %. After education there was no change in self-reported practices. At baseline nurses reported more difficulties than doctors. After education less difficulties were reported only in the domain of symptom alleviation. Better practices and more experience in PC weakly but significantly correlated with less difficulties in PC.
Conclusion: Tools for assessment of knowledge, self-reported practices and difficulties in PC were adapted for Slovenian environment. Using these tools at baseline good knowledge was found, with further increase after a two-hour course of education. Self-reported practices however did not change, but difficulties in the domain of alleviation of symptoms decreased. Additional educational courses would be necessary for significant improvement in practices and difficulties in PC.

Abstract number: E-46
Abstract type: Poster

What Role Do Death Cafés Play in Raising Awareness of Palliative Care? A Literature Review and Environmental Scan of Death Cafés in Alberta, Canada

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Background: Death Café is a grass-roots “social franchise” that has been embraced internationally as a means of facilitating relaxed conversations about death and dying. More than 12,000 Death Cafés have been hosted around the world since 2011. Many Canadian hospice and Palliative Care organizations have hosted Death Cafés, but their impact on, and application by, the palliative care community are not well understood.
Aim: Our purpose was to evaluate the state of the research evidence about whether Death Cafés are an effective tool for raising awareness of palliative care, as well as to assess the uptake of Death Cafés in the Canadian province of Alberta.
Method: An academic literature search was conducted using the MEDLINE, PubMed, CINAHL, Cochrane Library, PsycInfo, and Google Scholar databases, and a systematic search of past and upcoming Death Cafés in Alberta was undertaken on the Death Café website.
Results: Twenty-three articles met the literature search inclusion criteria. Death Café as a tool has not yet been subject to rigorous investigation. Despite significant interest in the Death Café model within the field of palliative care, there is very little evidence that participation in a Death Café leads participants to document their end of life wishes or to talk with their family and friends about death and dying. It is also unclear to what extent palliative care emerges as a topic of conversation at Death Cafés. The review of the deathcafe.com website yielded events organized by 34 facilitators in 23 municipal centres across Alberta since 2013. In eight of these locations, Death Cafés were hosted or facilitated by local hospice societies.
Conclusions: While evidence that Death Cafés raise awareness of palliative care is limited, they may lay the groundwork for palliative care by reducing fear and avoidance of conversations about death and dying.

Abstract number: E-47
Abstract type: Poster

Mentoring in the Time of COVID-19: A Narrative Review on Interprofessional Mentoring

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The COVID-19 pandemic has caused the redeployment of senior clinicians in Palliative Medicine, disrupting mentoring relationships which underpin mentoring’s success. This highlights the need for other members of the multidisciplinary team (e.g. nurses, social workers) to provide supplementary mentoring support such as through Interprofessional Mentoring (IPM). However, despite its increasing importance in the COVID-19 pandemic and with greater emphasis on the team-based approach in providing care, IPM is still poorly understood.
A narrative review, which used Krishna’s Systematic Evidence Based Approach, was carried out. The ‘Split Approach’ saw independent thematic analysis and directed content analysis conducted by two separate sub-groups of the research team.
A total of 3346 abstracts were reviewed, 104 full text articles were evaluated, and 23 articles were included. 4 themes were elucidated: [1] Definitions of IPM, [2] Mentees and Mentors in IPM, [3] Mentoring Stages, [4] Mentoring Environment and Host Organization. It revealed [1] that IPM remains poorly described, [2] specific traits of effective mentees and mentors, and benefits to both parties, [3] 4 clearly defined mentoring stages, and [4] various mentoring structures, cultures, and the benefits and barriers of a host organization.
IPM appears to be an evolution of novice mentoring and employs established novice mentoring frameworks, codes of conduct, and assessment methods to structure and oversee its approach. These results point to the need for further research on mentoring processes, dynamics of mentoring interactions, mentoring assessments, and policing of the mentoring process, and highlights how IPM is promising in the field of palliative medicine and may allow mentees to receive the support they need whilst building understanding between different professions.

Abstract number: E-48
Abstract type: Poster

Last Aid Courses Can Teach the Public about Palliative Care and Encourage Talking about Death and Dying in Many Countries

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Aims: Last Aid courses have been started to teach the public about palliative care with the aim to enable people to participate end-of-life care provision in the community. Today the International Last Aid working group includes members from 17 countries including Brazil and Australia. The aim of the present work is to provide an overview of the existing scientific evaluation of the effects of Last Aid courses for the public and to describe lessons learned from the implementation process.

Methods: Last Aid courses have been established in 17 countries. Research has been an integral part of the implementation process since 2015. An overview of the existing literature on Last Aid courses is provided. In addition a summary of the experiences from the implementation of Last Aid courses in different countries will be provided.

Results: Since 2015 a number of scientific papers and studies on the effects and implementation of Last Aid courses has been published. The results show that Last Aid courses are feasible and well accepted by the citizens in a number of different countries. Participants welcome the possibility to talk about death and dying and to learn end-of-life care. This includes both adults, teenagers and children. The implementation in different countries has shown that the Last Aid course is transferable to different nations and cultures. During the COVID-pandemic Online Last Aid courses have been started in Germany, Slovenia, Scotland and Brazil.

Conclusions: People aged from 9-100 in different countries appreciate Last Aid courses and want to talk about death and dying. During the COViD-pandemic Online Last Aid courses have been shown to be feasible and appreciated by the public.

Abstract number: E-49
Abstract type: Poster

It is High Time for Systematic Arrangements in Formal Education in Palliative Care

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Background: European recommendations emphasize the need for structured formal education for all health professionals, but in our country these recommendations have not been implemented yet.

Aims: The aim of the national research was to explore the curriculum of all secondary schools and higher education institutions (HEI) and establish how palliative care (PC) contents are recognised in curricula.

Methods: We analysed the curricula of twelve secondary schools of nursing, eight HEI of health sciences (seven faculties and one college), two Faculties of Medicine, one Faculty of Pharmacy, one Faculty of Social Work, and one Faculty of Theology. In next phase (in process) we have sent to these institutions the invitation letters, asking for more information about their curricula.

Results: Many physicians and nurses report that they have not received the required education in PC, not even basic knowledge during their undergraduate education. Based on online sources, we found that there are no clear data available for all schools. Two secondary schools of nursing have recognized the PC as an elective subject. The PC contents can be covered as part of various subjects. It is similar at the HEI of health sciences. Most often PC can be related to the professional field that lecturer covers. As a regular subject it is performed at one Faculty. At the postgraduate level, we have one master's degree programme in PC. At the other faculties, some elements of palliative care are included in other subjects. In the postgraduate education 3rd level, we have recognised only one elective subject. One Faculty of Medicine has a seminar in PC as part of the Oncology course and one Faculty as a elective subject.

Conclusion: More efforts are needed for the integration of PC into regular education programs on all levels. Further investigation is necessary to specify the current needs in PC education in our environment and to stimulate its successful integration in curriculums.

Abstract number: E-51
Abstract type: Poster

Analysis of Undergraduate Study Programs in Social Work and Psychology in Slovakia with a Focus on the Teaching of Palliative Care

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Background: As the care of dying patients and their families requires an interdisciplinary approach by several health and non-health professionals, we consider it very important to pay attention to the undergraduate education of professionals who focus on psycho-social care.

Aims: The aim is to analyze the content of study programs and the subjects themselves in the fields of social work and psychology in Slovakia with a focus on teaching palliative care.

Methods: We used a qualitative research design, in which we performed a content analysis of study programs and information sheets of subjects focused directly on the teaching of palliative care, or subjects that included palliative care. We studied study programs from all 34 universities and colleges in Slovakia, while we carried out a detailed analysis of all taught subjects at 7 universities and 3 colleges, which offered the study of social work and / or psychology.

Results: After an extensive content analysis of available materials, we state that the separate subject "Palliative Care" is in the field of social work included in the master's degree, or in the higher year of the bachelor's degree. Information related to palliative care is also taught in the subject "Social work in health care", "Gerontology" and others. The separate subject "Palliative care" is very complex. Our analysis showed that the subjects taught in the field of social work touch directly on the analyzed area, while the study of psychology is more general and in only one study program, we found the optional subject "Psychology in Palliative Practice". Information on palliative care is taught to a very limited extent in other subjects (e.g. Psychology of health and disease, Clinical Psychology).

Conclusion: Education in social work is focused more on palliative care than the study of psychology. On the positive side, subjects with a partial orientation in this area are part of the study plans of all universities and colleges considered.

Abstract number: E-52
Abstract type: Poster

A Systematic Scoping Review of Approaches to Nurturing Empathy in Palliative Medicine

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Background: Empathy is pivotal to effective clinical care of palliative patients yet the art of nurturing and assessing empathy in medical communities is rarely consistent and poorly studied. To inform future design of programs aimed at nurturing empathy in doctors and medical students, a review is proposed.

Methods: This systematic scoping review (SSR) employs a novel approach called the Systematic Evidenced based Approach (SEBA) to enhance the reproducibility and transparency of the process. This 6-stage SSR in SEBA involves three teams of independent researchers to evaluate 8 bibliographic and grey literature databases, followed by concurrent content and thematic analysis to evaluate the data that sees the findings expanded upon allowing an evidence based reproducible synthesis of this review.

Results: 24,429 abstracts were identified, 1188 were reviewed, and 136 were included for the analysis. Thematic and content analysis revealed 5 similar categories/themes including the definition of empathy; the approaches; assessment methods; outcomes; and enablers or barriers to nurturing empathy.

Conclusions: Nurturing empathy in palliative medicine occurs in stages underlining the need for the program to be part of a formal program built around a spiralled curriculum. We forward a framework built around the stages of nurturing empathy and focus attention upon effective assessments at each stage of the program. Tellingly there is also a need to consider nurturing of empathy's links with professional identity formation and the need for more effective tools to assess empathy and their role as part of a longitudinal and portfolio-based learning program.

F Posters Ethics, Policy and Law

Abstract number: F-01
Abstract type: Poster

Ethical Challenges and Decisions at the End-of-Life in Burn Intensive Care Units. Results from a Qualitative Interview Study

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Background: End-of-life care (EOL) and ethical decisions are a major step in the care provided to critically burned patients. Yet, EOL care is often neglected in burn intensive care units (BurnICUs). Dying, death, EOL care and ethical decisions are rarely studied in BurnICUs and often perceived as a clinical failure.

Aim: To explore the ethical challenges and decisions faced by professionals in BurnICUs.

Methods: Qualitative study with in-depth interviews. All 5 BurnICUs reference centres in Portugal (PT) were invited to participate; 3 participated. 15 professionals (12 nurses; 3 physicians) were interviewed from July to October 2020, until reaching theoretical saturation. A thematic content analysis was conducted to interview transcripts.

Results: Five main ethical challenges were identified: Intensifying pain and symptom control; Therapeutic obstinacy; Advance directives (ADs); Managing hope and expectations; Family involvement in the decision-making process. A main ethical challenge at the EOL in BurnICUs is intensifying pain and symptom control, including palliative sedation, once a consensualized decision to stop curative treatments is reached. However, professionals often struggle to identify whether or not they are acting with therapeutic obstinacy as the level of uncertainty associated to severe burn injuries is very high. “Giving-up” on curative treatments only occurs when “there is nothing else to escalate treatment options”. To aid in the decision-making process, ADs and family involvement are perceived as useful tools and strategies. Managing hope and expectations realistically is felt as a major ethical challenge.

Discussion/ conclusions: This is the first study in PT on EOL ethical challenges and decisions in BurnICUs using a qualitative approach to understand professionals' experiences. Findings suggest the need to further explore ethical challenges and the role palliative care can have to improve ethical decision-making at the EOL in BurnICUs.

Abstract number: F-03
Abstract type: Poster

Understanding Human Rights in Palliative and End-of-Life Care for Health Care Professionals

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Background: Understanding the human rights challenges associated with palliative care is important for health care professionals so that a person's rights to health and autonomy are realised.Care at end-of-life is a personal experience and autonomy is essential in delivering care which responds to the person's needs.

Aims: This project aimed to facilitate dialogue on palliative care from a human rights and equality perspective, build an awareness and understanding of the right to health and autonomy and provide an evidence base to inform practice.

Methods: Setup a steering group with experts from palliative care, law, and clinical practice. Online survey to identify a baseline of health care professionals' understanding of human rights. Reviewed human rights-based approaches for health that could be adapted. Facilitated a Q&A session with public and patient representatives and thematic analysis of data. Facilitated dialogue between health care professionals with legal and clinical experts in human rights and palliative care, using case presentations, and clinical and public and patient perspectives, during a pilot workshop. Supported national discussion through an online workshop, informed by the pilot workshop and accredited by professional bodies. Evaluated engagement pre-and post-event and developed an eLearning module.

Results: See Table.

Table 1. Sample of Quantitative and Qualitative Data.

Baseline Survey health care professionals in palliative care (n=35)
17% reported to have no knowledge of human rights in healthcare setting
20% reported they do not feel confident in incorporating human rights laws and practice
Q&A Session Themes public and patient (n=12)
Awareness and understanding of human rights needed for respectful decisions, communications, and quality of care for all
Lack of resources can diminish human rights
Human rights awareness is needed along with training in human rights for healthcare staff
Pilot and online workshop (n=31)
89% who completed evaluation reported significant positive change in their attitude towards explaining human rights to colleagues and service users after the workshop
Question: In your own words, what do you understand by a human rights approach to end-of-life care?
Respondent: lecturer/tutor with 20 years clinical practice in palliative care
Pre workshop: ‘Competence, Respect, Kindness, Dignity, Compassion and Access to services and medications.’
Post workshop: ‘Human rights are about autonomy and choice and ethical decision-making at end of life.’

Conclusion: For health care professionals to explore their understanding of human rights and palliative care, a forum for critical thinking must be supported by legal and clinical experts and involve clinical, public, and patient perspectives. This project has demonstrated that such a forum can support health care professionals to be able to describe, using their own words, a human rights approach to end of life care using concise and clear language. That significantly improves their ability to discuss human rights with colleagues and service users.

Funded: by IHREC.

Abstract number: F-04
Abstract type: Poster

Physicians' Perspective on Nonbeneficial Treatment when Assessing Patients with Advanced Disease for ICU Admission: A Qualitative Study

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Background: Providing nonbeneficial intensive care treatment to patients with advanced disease prolongs suffering at the end of life. It is associated with family distress and healthcare staff burnout.
Aims: To determine whether physicians integrate potentially nonbeneficial treatments in their clinical reasoning for ICU admission decisions and how they solve the question.
Methods: We conducted qualitative in-depth interviews with 12 ICU physicians and 12 internists working in the Geneva University Hospitals, a tertiary care hospital with 34 adult ICU beds. Interviews were analysed using an inductive approach to thematic content analysis.
Results: Physicians struggled to understand the request for intensive care for patients with advanced disease and full code status. Physicians considered patients' long-term vital and functional prognosis, but they also resorted to shortcuts, i.e. a priori consensus about reasons for admitting a patient. Family pressure and unexpected critical events were determinants of admission to the ICU. Patient preferences, ICU physician's expertise and collaborative decision making facilitated refusal. Physicians were willing to admit a terminally ill patient for a limited amount of time so he might fulfill a personal need.
Conclusions: In situations of potentially nonbeneficial intensive care, the influence of shortcuts or context-related factors suggests that practice variations and inappropriate admission decisions are likely to occur. Additional research should focus on how physicians weigh multiple contextual factors and how institutional guidelines and advance care planning, involving patients and their surrogate decision makers, can help admission decisions.
Funding: Swiss National Science Foundation, NRP 67 "End-of-life"

Abstract number: F-05
Abstract type: Poster

Reflections on Recruitment and Participation in a Randomized Placebo-controlled Multicentre Trial with Dying Patients – The SILENCE Study

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Background. There is a need for studies investigating symptom relief at the end of life. Randomised controlled trials (RCTs) are the gold standard for demonstrating efficacy of medication, but they are difficult to perform at the end of life as there are many barriers, such as the vulnerability of patients and gatekeeping by healthcare professionals.
Aim: To analyse and reflect on recruitment for and participation numbers in an RCT at the end of life.
Methods: In the SILENCE study, a randomised double-blind placebo-controlled trial performed in the hospices setting, we studied the effect of the prophylactic use of anticholinergic drugs on the occurrence of death rattle in patients who were in the last days or hours of life. We used several strategies described in the literature to overcome specific challenges for RCTs at the end of life: the used of advanced consent to address vulnerability, extensive training of health care professionals to minimise gatekeeping and the involvement and appointment of hospice doctors as daily responsible researchers to address unfamiliarity with research in hospices. We used well-known templates to collect data to prevent administrative burden.
Results: In total, 1097 patients were admitted of whom 626 were eligible at first assessment. Out of these 626 patients, 119 (19%) dropped out because of physical deterioration or sudden death before informing the patient about the study or signing informed consent. The strategy to avoid unjustified gatekeeping resulted in only 49 (8%) of 626 patients whom seemed eligible not being asked to participate. Overall 229 patients gave informed consent to participate in the study.
Discussion: Vulnerability of the patients and gatekeeping by HCPs are important barriers for research on medication use in the last days of life. The robust design and applied strategies to facilitate patient recruitment in the SILENCE study nevertheless resulted in sufficient participants.

Abstract number: F-06
Abstract type: Poster

Anticipatory Care Planning - Ethical Ambiguity

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Introduction: There is prevailing view within healthcare that anticipatory care plans (ACP) for people who are approaching end of life is universally desirable and beneficial. This is often couched in terms of respecting patient autonomy and allowing patients to exercise greater control in their care. However, this approach can minimise the potential harms of anticipatory care planning and the ethical ambiguity that can result.
Approach taken: From an ethical perspective it is clear that respect for individual autonomy is an important principle in healthcare. For example, in the United Kingdom (UK) there is a drive to reduce emergency admission to hospital and one way that it is felt that this can be achieved is by increasing the proportion of those patients who are likely approaching end of life (last 12 months of life) who have anticipatory care plans completed. The ethical implications of this are less discussed and it could be argued that it is ethically dubious to promote ACP in terms of personal autonomy, when in reality much of the impetus is from an economic concern. Equally, Covid-19 has brought ACP into the spotlight, with reports in the UK of blanket communications from healthcare professionals with certain groups of patients regarding limitations of medical treatment should they become seriously unwell due to Covid-19. This is the polar opposite of individualised and personalised discussions and has led some people to be suspicious of ACP more generally.
Conclusion: Without careful consideration of all the ethical aspects of ACP, there is a risk that it will become a contested area, with healthcare professionals promoting ACP unquestioningly and hearing and understanding the perspective of patients and families.

Abstract number: F-08
Abstract type: Poster

Advance Care Planning and informed Consent in Neonatology: A Qualitative Study on Family and Health Care Professional Experiences

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Background: The most commons situations of neonatal palliative care setting are 1) perinatal palliative care (do not reanimate order) and neonatal palliative care (limitations of intensive care). In this setting, Pediatric palliative care (PPC) has to adapt both to biological, relational and clinical characteristics of patients and new parents' social, ethical and spiritual ones. Developing a Pediatric Advance Care Planning (PACP) at an appropriate time can be defined a clinical and ethical duty. PACP should include an agreed approach to incorporating parents' ethical and cultural beliefs and values into the child care. Our project is aiming at qualitative explore parents and healthcare professionals (HPs) experiences of PACP in Italy, three years after the entry into force of the law on informed consent and advance care planning (L. n.219/2017).

Aims: To explore parents' meanings and experience with PACP; To explore HPs' experience in proposing and using PACP.

Methods: An inter-disciplinary research group developed a PACP document based on a literature review and the Italian law's ethical and legal principles. Then, HPs have been trained in using PACP document through theoretical lessons and role playing. In the third phase of the study, we will evaluate HPs and parents experience using semi-structured interviews and focus group.

Results: Between October 2019 and February 2020 we performed 10 hours of training with 12 physicians and 33 nurses working in the neonatology setting. During 2020 three families have been enrolled. Preliminary results of the study show a good response from HPs in terms of participation and appreciation of the training. The study is ongoing and final results will be presented during the congress.

Conclusion/Discussion: This study will produce qualitative evidence on PACP in the neonatology setting and represent the basis for developing and implementing a structured program in Italy to apply the law n.219/2017 in practice.

Abstract number: F-09
Abstract type: Poster

Bioethics Training in the Area of Health Sciences and the Opportunity to Palliative Care

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Background: In view of the planetary advancement of science/technology and its responses in care, there is an urgent need to resume ethical thinking and the Palliative Care approach that can support this predominance. In this sense, Bioethics as a discipline, and Palliative Care as a practical approach, become instances of protection of human interests against the hostile character of contemporary technoscience and risk of domination of human being.

Aims: To identify the theoretical-conceptual gaps of students from Health Sciences courses on key concepts for training in science/technique, ethics/bioethics, end of life and palliative care, and to discuss the possibility of new strategies for bioethical education and palliative care in these areas.

Design and methods: A qualitative research between Aug-Oct 2020 through an interview with students in the last year of the undergraduate course in Medicine, Nursing, Physical Therapy and Nutrition at a private university, *Teresópolis*, *Brazil*.

Results: 26 students were interviewed: Medicine 10, Nutrition 8, Physical Therapy 4, Nursing 2, but 2 excluded. The theoretical contents on science/technique were described in a assertive and more articulate way, while the concepts on ethics were more elusive - in the deontological area, on bioethics were superficial - in a principles biomedicine ethics tendency, and a misunderstanding speech of end of life, and similarly, scarce or absent palliative care education and its application in courses.

Conclusions: The struggle of dialogue between health sciences and the humanities areas states that there is a gap in the training of students, especially in a fair appropriation of knowledge in the area of Bioethics and Palliative Care. The authors consider an opportunity for improvement in teaching strategies that may enhance the development of an ethical conscience capable of modifying attitudes and behaviors of future health professionals.

Abstract number: F-10
Abstract type: Poster

Identifying Patient Values Impacting the Decision Whether to Participate in Early Phase Clinical Cancer Trials: A Systematic Review

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Background: Treatment decisions call for discussions of medical-technical information and patient values. The latter are even more important in decisions regarding early phase clinical trial participation (EPCTP); experimental treatments for which no evidence of efficacy is available yet. Although some patients are aware of palliative care services as alternative for EPCTP, not all consider these for themselves, which could interfere with adequate end-of-life decision-making. Discussing patient values could support patients to make a decision in line with their personal values. This systematic review is the first, to our knowledge, to provide an overview of patient values surrounding EPCTP.

Aims:

(1) To synthesize and describe which patient values play a role in the decision-making process for EPCTP;
(2) to indicate how these factors relate to the decision (or not) for EPCTP.

Methods: We conducted a systematic search in 7 electronic databases on patient values (i.e. desires, goals or beliefs that people can find important in this context of a life-limiting disease) in the decision-making process for EPCTP.

Results: From 3072 retrieved articles, 11 quantitative and 5 qualitative studies met our inclusion criteria. We extracted 10 values that contribute to patients' decisions. Overall, quality of life and humanity were reported by patients who refuse EPCTP. (Combinations of) hope, trust, quantity of life, altruism, perseverance, faith and risk tolerance were reported by patients who seek EPCTP. Autonomy and social adherence were reported by both seekers and refusers of EPCTP.

Discussion: This analysis reinforces the central role of individual exploration of values by healthcare professionals and patients in the context of EPCTP and palliative care. Patients who become aware of their values could feel more empowered to make a decision. Eventually, this might ensure that patients spend the time left towards their end of life in a way that suits their main values.

Abstract number: F-11
Abstract type: Poster

Construction of a Resource for Advance Care Planning in Multiple Sclerosis (ConCure-SM): Results of Cognitive Debriefing with Users

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Background: ConCure-SM is a mixed-methods research project for developing and testing an advance care planning (ACP) intervention for people with progressive multiple sclerosis (pwPMS) in Italy. It consists of a booklet to be used during the ACP conversation (the focus of this presentation) and a training program for neurologists and other MS healthcare professionals (HPs).

Aims: To assess the acceptability and comprehensibility of the ConCure-SM booklet.

Methods: An inter-disciplinary panel translated and adapted to the Italian legislation and to the MS context a booklet developed by the National ACP programme for New Zealand. The booklet was then probed via individual cognitive interviews with pwPMS and caregivers, and a focus group meeting (FGM) with MS HPs. Two weeks before the interview/FGM, held on digital platform due to the COVID-19 pandemic, participants received the booklet and were invited to browse it.

Results: Between September-January 2021 we conducted 13 interviews which lasted between 36 and 80 minutes. Participants were 10 pwPMS and 3 caregivers (2 spouse, one daughter); 8 were men, median age was 54 years. Data saturation was achieved after 11 interviews were analyzed. Twelve HPs participated in the FGM (7 neurologists, 3 psychologists, one nurse and one physiotherapist), which lasted 1.45 min. Thematic analysis (performed by LDP, SV, and LG) identified 4 overarching themes: comprehensibility and clarity; content acceptability and emotional impact; images and layout; suggestions for improvement. Interviews revealed that the booklet was useful and informative, though pwPMS found it emotionally taxing. The FGM was well participated; few experiential data on ACP emerged, lack of training and time constraint emerging as major reasons.

Conclusions: Cognitive debriefing was key to refine the ConCure-SM booklet. Interview and FGM results corroborated use of the booklet within the ACP conversation, and the challenge of appraisal as a standalone tool.

Abstract number: F-12
Abstract type: Poster

Italian Validation of the Go Wish Game: Preferences and Values at the Center of End-of-Life Choices

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Background: The Go Wish Game (GWG) is a tool to supports patients, families and health care professionals (HPs), to discuss and share their values and priorities of care, especially for the end of life (EOL). The GWG consists of a guide and 35 cards helping persons to think about their personal values. GWG has been already translated into many languages across different countries. The Italian validation of the GWG would improve the implementation of advance care planning (ACP) discussion among HPs and patients.

Aims: The study aims to translate and cultural validate the GWG in the Italian setting.

Methods: We followed the I-V steps of Beaton et al. to translate and propose a cross-cultural adaptation of the GWG into Italian. We provided firstly a back-forth translation to guarantee the linguistic appropriateness between the translated and the original version, involving also the author of the GWG for an external feedback. Then, we developed a prefinal Italian version. To assess feasibility and content validity, this version was qualitatively evaluated through two focus group (FG), respectively with HPs potentially involved in ACP discussion and representatives of local patients' associations.

Results: On February 2021 we conducted one FG with 8 HPs (6 physicians, 1 psychologist and 1 nurse) which lasted 1:42:51, and one FG with 5 patients' association representatives which lasted 1:43:02. Thematic analysis identified three main themes: the importance of being supported, the relevance of an elegant and friendly language, the lack of some peculiar cultural aspects. Final results will be presented during the congress. The prefinal Italian version is characterized by less explicit statements towards EOL choices.

Conclusion: We can suppose that the Italian validation can be both feasible and cultural appropriate to the Italian context and can help in the implementation of ACP three years after the entry into force of the Italian law on Informed consent and advance directives.

Abstract number: F-13
Abstract type: Poster

219/2017 Italian Law "Rules on Informed Consent and Advance Processing Provisions" - Barriers and Application Strategies in Pediatric Palliative Care

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Italian Law 219/2017 defined the informed consent's rules and the right for advance care plan, in according to the bioethical principle of autonomy, and considering the appropriateness of the proposed treatments. The bioethical principles of beneficence, non-maleficence, autonomy and justice can really be an important basement for discussion about appropriateness and proportionality of the proposed treatments. In Pediatric Palliative Care (PPC), the implementation strategies of shared care plan and advance care plan, guaranteed by Law 219/2017, can raise different critical issues. First of all, in PPC, guaranteeing adequate information to the child, taking into account his ability to understand, and giving to the child the possibility to express his wishes, requires dedicated communication skills and, at the same time, the parents' awareness about the importance of child involving in the shared care plan, especially with adolescents. In the absence of these dedicated skills, the "protective style" in the communication, adopted particularly with poor prognosis' incurable diseases, ends up to exclude the child from the shared care plan, with important consequences in the end of life time. To identify the child's role, as well as the parents' role, such as the care team's role, in the definition of the shared care plan is crucial. The child best interest have to be guided by child will, considering his skills to express it, and by the parents' will too. In case of great disagreement the Pediatric Committees for Clinical Ethics has to be considered for more deep discussion; this also if persistent disagreement between parents and the care team, or adolescent and care team, or adolescent and parents. In PPC the uniqueness of each case has to be considered in order to identify the best interest of the child and the more effective implementation strategies of the 219/2017 Italian Law.

Abstract number: F-14
Abstract type: Poster

'Intermittent Sedation Is Sometimes an Alternative to Assisted Suicide': A Multicentre Qualitative Interview Study with Palliative Care Physicians in Switzerland

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Background: According to the European Association for Palliative Care, decisions about palliative sedation should not be made in response to a request for assisted dying. However, some international studies have shown that sedation has been considered as an alternative to assisted dying in countries such as the Netherlands and Belgium. In Switzerland, where assisted suicide is decriminalized and palliative sedation is not regulated by law, no studies have comprehensively investigated the relationship between requests for assisted suicide and palliative sedation practices.
Aims: To explore palliative care physicians' experiences of sedation as an alternative to assisted suicide in the French-speaking part of Switzerland.
Methods: A multicentre qualitative study based on interviews with palliative care physicians in the French-speaking part of Switzerland followed by linguistic and thematic analysis of all the interview transcripts.
Results: The participating physicians worked in four different palliative care institutions located in three states in Switzerland. Of the twelve interviews conducted, ten were included in our analysis. We categorized the different types of sedation that emerged from the analysis as 'temporary', 'intermittent', and 'gradual/rapid continuous deep sedation until death'. Temporary and intermittent sedation are only used in response to a request for assisted suicide. This is due to the fact that assisted suicide can sometimes not be realized at home for medical reasons or in order to protect the family.
Conclusion: These results may be relevant for professionals when reflecting on this difficult clinical, ethical and legal subject, as well as when developing recommendations or institutional protocols on palliative sedation. The potential impacts of considering palliative sedation as an alternative to assisted suicide in palliative care settings should be qualified in the context of an open and honest societal debate.

Abstract number: F-15
Abstract type: Poster

End-of-Life Palliative Care Patients with Cardiac Implementation Electronic Devices: Admission Rate Trend at an Italian Palliative Care Service

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Background: The number of patients with Cardiac Implementation Electronic Devices (CIEDs) is increasing, but little is known about the end-of-life (EoL) care of these patients. While the CIEDs improve survival and quality of life of patients with heart diseases, they may no longer be consistent with the goals of care for terminally ill patients. Because implantable cardioverter defibrillator (ICD) shocks can trigger pain, discomfort, anxiety and prolong life with unacceptable quality, multiple recommendations promote proactive conversation about ICD deactivation in patients with advanced disease.
Aims: The aims of the study are to examine the trend of palliative care annual admission rate of patients with CIEDs as well as to explore theirs advance directives attitudes.
Methods: This was designed as a cross-sectional study, conducted between 1*th*February 2018 and 1*th*February 2021 in a sample of end-of-life palliative care patients in hospice or at home. Patients' sociodemographic and clinical data, device type, goals of care communications and advance directives are collected in a web-based Case Report Form.
Results: Data collection is in progress and final outcomes are expected in march 2021. The analysis will identify the results which will be presented at the congress. The results will inform on: the annual rate trend of end-of-life patients with CIEDs admitted to an Italian palliative care service during the last three years; the type of device; the preferences for EoL sustaining treatments. These results will provide a framework three years after the approval of first advance directive legislation in Italy (no. 219 of Dec 22th 2017).
Conclusion/ discussion: To the best of our knowledge, the present study represents the first Italian investigation of palliative care patients with CIEDs. The use of CIEDs involve increasing clinical and ethical skills of healthcare professionals and reflecting on the goals of care and communication with these patients.

Abstract number: F-16
Abstract type: Poster

Shifts in Consultation of Specially Trained Physicians in the Context of a Euthanasia Request: A Repeated Cross-sectional Survey, 2008 versus 2019

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Background: In case a person requests euthanasia, Belgian law stipulates that the treating physician needs to consult with an independent physician as a procedural safeguard. In Flanders and Brussels, the Life End Information Forum (LEIF) trains physicians to perform expert consultations in the context of such requests. Evaluation of these consultations provides important insights into the safety and quality of euthanasia practice.
Aims: To compare characteristics and activities surrounding LEIF physicians' consultations for euthanasia requests in 2019 with those in 2008.
Methods: A repeated cross-sectional survey conducted in 2008 (N=128) and 2019 (N=458) among all qualified LEIF physicians in Belgium. Questions about case characteristics and consultation activities in the most recent consultation in the context of euthanasia requests in 2019 were identical to those asked in 2008.
Results: The response rate was 75% in 2008 and 54% in 2019. The proportion of patients aged 80 years or older increased from 9% to 31% (p=0.001) and the proportion of patients with cancer as the main diagnosis decreased from 70% to 53% (p=0.034). Dependency was more frequently indicated as a reason for requesting euthanasia in 2019 (29% vs 54%, p=0.002). Regarding independence between attending and consulted physician (which is a legal safeguard), 87.9% was not a colleague from the same hospital in 2019, 97.7% was not from the same practice, and 96.9% was not a co-attending physician. Unbearable suffering (65% vs 87%, p=0.003) and alternative treatments (palliative: 13% vs 48%, $p<0.001$; curative: 5% vs 28%, p=0.002) were discussed more often in 2019. In 2019, 64.1% of patients were granted euthanasia, compared to 69.1% in 2008 (p=0.531).
Conclusion: We identified shifts in the characteristics of patients requesting euthanasia. Our findings point to improvements in (legal) standards for quality consultation e.g., discussion of suffering and alternative treatments with attending physicians.

Abstract number: F-17
Abstract type: Poster

"Too Late or Too Soon": The Ethics of Advance Care Planning in Dementia Setting

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Background: The number of people living with dementia has been increasing worldwide, leading for discussion on the ethical aspect of heath care relationship in dementia care. Advance care planning (ACP) represents a pivotal aid in the decision-making process. It can be especially controversial for people with dementia, who inevitably will lose the capacity to make decisions regarding treatments, not only at the end of life. In Italy, ACP is regulated by the Law n. 219/2017 on informed consent and advance directives. To date, few studies investigated its impact on the care of patients with dementia.
Aims: To comprehend the perception of physicians who provide care for patients with dementia regarding ACP and to describe their difficulties and needs.
Methods: We choose a phenomenologically oriented qualitative design using semi-structured interviews with physicians caring for dementia patients.
Results: Between November 2018 and March 2019 we performed 11 interviews which lasted a mean of 34'. Participants were 11 physicians (2 palliative physicians, 2 neurologists, 7 geriatricians).The interpretative phenomenological analysis identified 4 macro-themes related to: the uncertainty and difficulties in shaping the healthcare relationship, the role of family members in dementia care, the difficult identification of the right decision at the right time, and further needs to improve ACP in the Italian context.
Conclusion: Data show that physicians experience the difficulty to synchronize the times required by ACP with the rapid decline of dementia. Further investigations are needed in order to both implement and evaluate trainings on ACP specific communication, and organize a broader involvement of institutions in ACP provisions.

G Posters Disadvantaged Populations

Abstract number: G-01
Abstract type: Poster

Palliative Care and Homelessness – Developing Communities of Practice to Address Inequity in Palliative Care Access

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Background: People in UK homeless hostels experience extremely high rates of multi-morbidity, frailty and age-related conditions at a young age but seldom receive palliative care. The burden of support often falls to hostel staff. Before COVID-19 we evaluated a model embedding palliative specialists into hostels to provide support to staff and residents and facilitate a multidisciplinary approach to care. Subsequent to the pandemic we have adapted our model to develop online communities of practice to facilitate interdisciplinary learning and working.
Aims: Improve care and support received by people experiencing homelessness who may benefit from a palliative approach by developing communities of practice to connect and empower those that support them.
Methods: A range of homelessness, health and social care professionals within different locations, attended a series of seven online sessions. Presentations from experts were shared and discussed with a focus on how practice in local areas could be adapted to provide a person-centered approach to support those with deteriorating health. Participants were also encouraged to use the sessions as a vehicle for developing a multi-professional response to challenges encountered in real time. Data were collected via surveys and focus groups throughout, and three months after, completion of sessions.
Results: We will explore usefulness of component parts of training regarding; understanding and working effectively in a person centered, trauma-informed way and increasing knowledge of a palliative approach. We will also explore feasibility of building communities of practice for connecting professionals supporting people experiencing homelessness for ongoing support and collaboration.
Conclusion / discussion: To address the inequity that exists in palliative care access for people experiencing homelessness, a joined up, supportive, multi-professional response is essential.

Funded by The Oak Foundation

Abstract number: G-04
Abstract type: Poster

Being Known: How People from Minority Ethnic Communities with Terminal Illnesses Navigate the Healthcare System as 'Whole' Individuals with Potentially Diverse Needs

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Background: The Thinking Ahead study explores how terminally ill patients from Black Asian and Minority Ethnic (BAME) backgrounds and their family care givers (FCGs) think ahead about deterioration and dying and engage with healthcare professionals (HCPs) to optimise care. This paper reports a key finding that engagement and willingness to consider or discuss end of life care is enhanced if patients and FCGs feel 'known' by HCPs, in whom they then place trust. Conversely, they may feel alienated and that they have little purchase within a system that does not recognise them. This may inform UK policy prioritisation of effective end of life care planning (EOLCP).
Aims: To explore experiences of 'being known' and the impacts on patients of navigating healthcare particularly in talking about end of life and preferences for care.
Methods: A qualitative study including comparative thematic and cross case analysis from 18 longitudinal patient case studies (93 interviews) and 19 interviews with bereaved FCGs.
Results: Participants described a range of challenges to 'being known'. Some stemmed from communication impairments associated with illness, mental capacity or because English was not their first language. Compounding such practical challenges were systemic barriers leaving people feeling 'dislocated' in a complex, bureaucratic system where information was not easily shared between HCPs or departments working in silos. Often the re-telling of salient information was requested at consultations. Prior, negative experiences of healthcare greatly impacted future expectations and trust.
Conclusion: Systemic barriers leading to HCPs not 'knowing' patients constrained their ability to personalise care, especially in initiating discussion about end of life care preferences and exploration of cultural and religious factors shaping these. Consequently, opportunities to optimise end of life care for BAME patients were lost as were UK policy priorities for effective EOLCP.

Abstract number: G-06
Abstract type: Poster

Examining the Association between Ethnicity, Socioeconomic Deprivation and Receipt of Hospital-based Palliative Care for People with Covid-19 - A Dual Centre Case Series in the UK

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Background: COVID-19 has highlighted health inequalities experienced by people from ethnic minority groups and deprived socioeconomic backgrounds. It is unclear whether these characteristics are associated with later referral to palliative care.
Aims: To examine the association between ethnicity, deprivation, and timing of palliative care referral for patients with COVID-19.
Methods (design, data collection, analysis): Service evaluation using patient data from two London hospitals. Data on inpatients with confirmed COVID-19 referred to the hospital palliative care service February-May 2020 were included. Patients were coded into white and non-white ethnic groups. Sociodemographic (age, sex, Index of Multiple Deprivation, ethnic group) and clinical variables (Charlson comorbidity index, reason for admission) were described. The association between ethnicity and socioeconomic deprivation with timing of referral to palliative care (days from admission to referral) was explored using a multivariable Poisson regression model.
Results: 334 patients were included. 119 (36%) were from a non-white ethnic group; most commonly Black British 77 (23%) and Asian British 26 (7.8%). Patients of non-white ethnicity were more likely to be younger, male and have higher levels of socioeconomic deprivation. A longer time between admission and palliative care referral was associated with male gender (IRR 1.23, 95% CI 1.14-1.34) and lower levels of socioeconomic deprivation (IRR=1.61, 95% CI 1.36-1.9). Non-white ethnicity was not associated with a difference in time to palliative care referral (IRR=0.96, 95% CI 0.87-1.05).
Conclusion / discussion: In this large dual-centre case series of people with COVID-19, there was no evidence that patients from non-white ethnic groups or more deprived socioeconomic groups had longer time to palliative care referral. Ongoing monitoring of data is needed to ensure equitable delivery of services.

Abstract number: G-07
Abstract type: Poster

In-Dialogue: Consensus on a Conversation Aid for Shared Decision Making in the Palliative Phase

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Background: As people with intellectual disabilities (ID) grow older, palliative care is becoming increasingly relevant for them. ID care professionals find it difficult to involve people with ID in making decisions about treatment and care in the palliative phase. A shared decision making (SDM) aid may be useful to achieve better alignment of care to values and needs of people with ID.
Aims: To develop a SDM conversation aid to enable involvement of people with ID in the palliative phase in making decisions and to evaluate its relevance and feasibility .
Methods: Based on an existing SDM model for frail older patients, literature and expert opinions, we developed a draft conversation aid for people with ID (In-Dialogue). In a Delphi consensus process, an expert panel of 11 people with ID, 14 relatives and 65 healthcare professionals completed 2 rounds of online questionnaires about the relevance and feasibility of the components of this conversation aid.
Results: Based on the first round of the expert panel's feedback, we subdivided the In-Dialogue aid into 4 themes: who are you; illness/end of life; making a decision; and evaluating the decision. In the second and final round, components were considered relevant by 67-97% of the panel members (*M*=90%) and feasible by 66-86% (*M*=77%). Panel members with ID indicated that black and white icons were too abstract and asked for the use of illustrations in which the context of a situation was more apparent. The final In-Dialogue conversation aid comes in a box with a pad which resembles a board game, 13 conversation cards, 50 supporting illustrations, a workbook and an accompanying manual.
Conclusion: The Delphi panel considered the consensus-based conversation aid to be sufficiently relevant and feasible to be implemented in practice. The involvement of people with ID ensured that their needs and wishes were taken into account in the development of the In-Dialogue aid. This research was funded by ZonMw, grant 844001503.

Abstract number: G-08
Abstract type: Poster

Project ECHO™ Palliative Care: Impact of Tele-mentoring and Teaching for Healthcare Providers working with Rohingya Refugees in Bangladesh

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Background: The humanitarian health response is often focused on efforts to save lives, while needs of individuals with incurable conditions are often neglected. Palliative care training for humanitarian healthcare providers (HCPs) has not been incorporated into humanitarian responses. Project ECHO is an established distance-education model that seeks to develop a virtual community of practice to build capacity among HCPs, and has been successfully used to support HCPs providing palliative care in South Asia.
Aims: To develop, implement, and assess the impact of a Project ECHO for Humanitarian Palliative Care in the Rohingya Refugee Crisis in Bangladesh. Our objectives were to assess participation, program acceptability, changes in self-efficacy and attitudes towards palliative care among HCPs as well as self-reported practice changes after six months.
Methods: Electronic surveys were distributed at baseline and after 6 months.
Results: The program consisted of 7 ECHO sessions (75-minutes) conducted regularly from September-October 2020. There were 75 participants. Survey respondents included nurses (45%), physicians (45%), and other health care professionals (10%). The majority (60%) worked at community-level or primary care clinics (very few more specialized facilities in the region), and 60% were responsible for caring for ⩽ 10 patients requiring palliative care per month. Comfort and attitude scores showed improvements after participation, with stronger improvements noted in self-efficacy identifying people who might benefit from palliative care, discussing the role of palliative care, breaking bad news to families, and in treating pain.
Conclusions: Project ECHO suggests a novel educational model that can be used to support primary HCPs in humanitarian settings. We continue to see the positive impact of the program as local HCPs have continued to participate in ongoing tele-mentoring sessions offered monthly since this ECHO program was completed.

Abstract number: G-09
Abstract type: Poster

Out-of-Pocket Costs Near End of Life in Low- and Middle-income Countries: A Systematic Review

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Background: Globally, there is a rise in non-communicable disease, including cancer, major organ failure and dementias. Patients and their families in low- and middle-income countries (LMICs) pay a high proportion of medical costs out of pocket (OOP), and a diagnosis of serious illness often has catastrophic financial consequences. We therefore conducted a review of the literature to establish what is known about OOP costs near end of life in LMICs.

Aims: To identify, organise and report the evidence on out-of-pocket costs in adult end-of-life populations in LMIC.

Methods: A systematic search of 8 databases and a hand search of grey literature was performed. Two independent reviewers screened titles and abstracts, assessed papers for eligibility and extracted data. The review was registered with PROSPERO and adhered to the Preferred Reporting items for Systematic Reviews and Meta Analyses. The Mixed Methods Appraisal Tool was used to assess quality. The Wagstaff taxonomy was used to describe OOP.

Results: After deduplication, 9343 studies were screened, 49 full-text articles were assessed for eligibility and 12 were included in the final review. OOP were higher for those subjects who died in hospital versus at home, and increased with advanced illness and disease severity. The main drivers of OOP were medications and hospitalizations, with high but variable percentages of the affected populations reporting financial catastrophe.

Conclusion: Despite a small number of included studies and heterogeneity in methodology and reporting, OOP for care near end of life in LMIC represent an important source of catastrophic health expenditures and impoverishment. This suggests a role for widespread, targeted efforts to upscale palliative care provision in LMIC, as a poverty reduction strategy. Financial protection policies for those suffering from incurable disease and future research on the macro- and micro economics of palliative care delivery in LMIC are greatly needed.

Abstract number: G-10
Abstract type: Poster

A Personalised Approach isn't Always Enough - Specialist Palliative and Hospice Services Response to People from Ethnic Minority Groups Diagnosed with COVID-19: An Observational Study (CovPall)

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Background: The disproportionately high death rate of those from ethnic minority groups from COVID-19 is well documented. Little is known about how palliative care services have responded.

Aims: To map and develop insights into the response of palliative care services caring for patients and families from ethnic minority groups during the COVID-19 pandemic.

Methods: (design, data collection, analysis): Cross-sectional on-line survey of UK palliative care services' response to COVID-19. Quantitative data were summarised descriptively and chi-square tests used to explore relationships between categorical variables. Open-ended responses were analysed using reflexive thematic analysis.

Results: 93/277 (34%) responding palliative care services reported on care for COVID-19 patients from ethnic minority groups (60/123 (49%) hospital palliative care teams and 35/152 (23%) hospice inpatient teams). Nearly two-thirds (59%) of services offered care across multiple settings. Services who supported those from ethnic minority groups were more likely to have hospital palliative care teams (χ^2 =15.21, p $<$0.001) and less likely to have inpatient hospice ($\chi^2 = 30.11$, p $<$0.001) or home palliative care teams ($\chi^2 = 7.05$, p= 0.008). 61/93 (66%) responding services stated there was no difference in how they supported or reached ethnic minority groups. Five main themes were identified from free-text comments:

1) disproportionate adverse impact of restricted visiting
2) compounded communication challenges
3) unmet religious and faith needs
4) mistrust of services and
5) equal but inequitable service response.

Conclusion / Discussion: Policies introduced during the COVID-19 pandemic may have disproportionately adversely impacted those from ethnic minority groups. The palliative care response may have been both unequal and inequitable. The traditional focus of personalised care is not enough. We provide urgent recommendations for service providers and policymakers.

Abstract number: G-11
Abstract type: Poster

Facilitating Access to Hospice Care in Socially Deprived Areas: A Mixed Methods Multiple Case Study

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Background: While there have long been concerns that social deprivation is associated with access to hospice care, there is uncertainty about the factors influencing access in the most socially deprived areas.

Aim: This study aims to explore the association between hospice referrals and area social deprivation, and the factors influencing access to hospice care in the most socially deprived areas.

Methods: Access to hospice care was explored in three different areas of North West England using a mixed methods multiple case study approach. Data relating to hospice patients, referrals, and area characteristics were analysed using Poisson mixed models and multiple linear regression. Qualitative interviews with specialist and generalist palliative care professionals were analysed using thematic analysis. Each area was analysed individually before comparing findings in a cross-case analysis. Data from 8699 hospice patients and 42 healthcare professionals contributed to the study.

Results: Social deprivation was not statistically significantly associated with hospice referral rates in any of the three areas (Area 1, Incidence Rate Ratio (IRR) 1.04, p=0.75; Area 2, IRR 1.09, p=0.15, Area 3, IRR 0.88, p=0.35). Access to hospice care in socially deprived areas was influenced by how hospices adapted to local organisational and population contexts. Good working relationships with hospitals may have facilitated hospice referrals of patients from the most socially deprived areas.

Discussion: Hospice care in the UK can be organised in ways that facilitate referrals of patients from the most socially deprived areas, although uncertainty about what constitutes need for hospice care limits conclusions about equitable access. This study encourages an understanding of access that goes beyond referrals to consider how access to hospice and other end-of-life care is continuously generated in interactions between healthcare professionals and patients.

Abstract number: G-12
Abstract type: Poster

Facilitators and Barriers to Access and Utilisation of Palliative Care among Non-western Migrants: A Systematic Review

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Background: Non-western migrants living in Europe, have a tendency to lower utilisation of existing hospice and palliative care at the end of life.
Aim: To identify and describe published research on the European evidence on facilitators and barriers to access and utilise palliative care among non- western migrants.
Methods: A systematic review in accordance with PRISMA guidelines was conducted on 26*th* of June 2020, searching Medline, CINAHL, PsychINFO and EMBASE databases. Search words were for example ethnic groups and palliative care. Studies included empirical research and published between 2011 and 2020. Thematic analysis was used to analyse data.
Results: [MR1] Of the 116 articles meeting the inclusion criteria, thirty-five articles were included, 29 qualitative and 6 quantitative. More than half of all articles were conducted in UK (n=19), followed by Netherlands (n=4), Germany (n=3), Belgium (n=3), Sweden (n=2), Norway (n=2), Austria (n=1), and Denmark (n=1). Three main themes were identified 1. poor communication and poor language proficiency of the migrants, 2. lack of knowledge and awareness among migrants about the existing palliative care services and 3. lack of resources at different levels of palliative care service provision. Identified themes result in barrier to access and utilise existing palliative care services. To facilitate utilisation of palliative care among migrants provision of professional interpreter, flexibility of health care facilities to embrace diverse patients, and cultural competent training towards health professionals were suggested in articles.
Conclusion: This review highlights that barriers exist in the system, and at community and individual level, yet, recommendations are mostly at individual level. Thus, it will be worth noting existence of the challenges on different levels while deigning intervention to ensure equal access.

Abstract number: G-13
Abstract type: Poster

Gender Gap in the Illness. Measuring the “Gender Financial Toxicity Gap” in Cancer Patients Receiving Home-based Palliative Care

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Aim of the work: The COmprehensive Score for financial Toxicity (COST) is considered a validated measure to assess financial toxicity in patients with cancer. Does the gender gap influence financial toxicity? The European Institute for Gender Equality (EIGE) compares yearly mean monthly earnings of women and men (“gender earnings gap”). In Italy, women’s mean monthly earnings amount to almost a fifth less (-17,57%) than men’s (EIGE, 2020). The study is aimed at examining the “Gender financial toxicity gap” evaluating differences in COST values among patients with respect to gender. Observation of our organisation’s data on palliative care services provided in 2020 highlights that, among people aged less than 67 years (still not retired), women demand more palliative care services than men. Since cancer is very often associated to unemployment and poor work ability, can these women cope with growing medical and non-medical expenses and bear the financial burden of the illness? Unfair working conditions imposed to women imply a higher COST value and suggest that grade of financial toxicity is significantly influenced by gender.
Methods and approach taken: In order to collect empirical data on financial distress related to the course of the illness, our organisation is measuring the “gender financial toxicity gap” using the COmprehensive Score for financial Toxicity (COST).
Results: Financial toxicity hits more women than men. Cancer reinforces inequality and widen disparities, and as disease progresses, the “gender financial toxicity gap” tends to widen. Our data show a significant “gender financial toxicity gap” within the sample observed.
Conclusion: Cancer exacerbates inequalities and widens the gender gap. Policy initiative should consider solutions to tackle “gender financial toxicity gap”, in order to guarantee all cancer survivors appropriate financial means to sustain out-of-pocket costs and deal with the illness. The study is self-financed.

Abstract number: G-15
Abstract type: Poster

Palliative and End-of-Life Care, People with Intellectual Disabilities & Covid-19 (PEPIC-19): An International Survey

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Background: People with intellectual disabilities (ID) have worse health outcomes and face inequalities at the end of life. It is not clear how Covid-19 has affected end of life care.
Aim: To gain insight into the perceived COVID19 related changes in provision, quality and challenges of palliative and end-of-life care to people with ID in countries across the world.
Method: An international anonymous online survey, aimed at health/social care professionals, was developed by 15 researchers from 10 countries (part of the EAPC Reference Group on Intellectual Disabilities). It was based on the 2015 EAPC White Paper on ID describing 13 good practice norms. Data were analysed using descriptive statistics, with content analysis of free text.
Results: 471 respondents from 19 countries completed the survey between Oct 2020-Mar 2021 (88% health/social care professionals, 12% academic/educators). North West Europe was over-represented, but responses were received from other countries including USA, Australia and Asia. Areas of end-of-life care most frequently reported as less in line with the 13 investigated norms were “adequate bereavement support for people with ID” (40%) and “adequate training/support for healthcare staff” (40%). Areas showing the greatest concordance with these norms were “access to hospital care when needed” (62%) and “families involved in end-of-life decisions” (50%). Areas that most respondents reported as worse during the pandemic were “people with ID attending funerals” (57%), “opportunities for families to be involved in care” (49%) and “adequate support from health/social care professionals for the end of life needs of people with ID” (41%).

Conclusion: There are significant challenges in providing end of life care for people with ID, these have been exacerbated by Covid-19. This survey provides important indicators for developing policy, practice and research priorities, and is a starting point for further research.

Abstract number: G-16
Abstract type: Poster

Trust in Older Black, Asian and Minority Ethics Persons with Dementia and Caregivers: The Effects of COVID-19

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Introduction: Members of Black, Asian and minority ethnic (BAME) communities in the UK have faced significant burden due to COVID-19. This population has had higher incidence rates of COVID-19, and also higher death rates. The pandemic has also disproportionately affected older adults, including those with dementia and as a result their caregivers. This study aims to explore culturally specific experiences of trust surrounding government policies, guidelines and services in BAME populations in the UK.
Methods: Semi-structured interviews with 11 caregivers and 7 older adults with dementia were performed as part of a wider study on BAME experiences under COVID-19. Participants were recruited from national registries, such as Join Dementia Research, social media and word-of-mouth. Data was then analysed using thematic analysis methods with a specific focus on experiences around trust in guidelines, services and policy.
Results: The concept of trust featured heavily in respondent interviews. Trust was seen as both a personal and a wider community issue. When stratified by ethnicity (within BAME communities) and other demographic factors, differences in level of trust and perception of guidelines and policies were found between groups – such as how much trust was put into government messaging.
Conclusions: This paper looks at groups highly vulnerable to COVID-19 and their experiences of health and social policy. It is clear that attention must be paid to differences between different groups' cultural norms and structures in formulating and providing health and social care interventions. A move away from "one-size-fits-all" policies may improve both the experience of health and social care interventions and promote feelings of inclusion and trust towards providers.

Abstract number: G-18
Abstract type: Poster

Estimating Palliative Care Needs of Women with Cervical Cancer

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Background: Cervical cancer is a grave threat to women's well-being and disproportionately afflicts the poor. Available data suggest that women with cervical cancer typically experience complex and severe suffering.
Aims: We studied the most common types of suffering due to cervical cancer, their severity, prevalence, and duration.
Methods: We reviewed the literature on the major types, severity, prevalence, and duration of suffering due to cervical cancer. We then conducted a modified Delphi process with cervical cancer experts to supplement the literature. We distinguished between decedents (those who die from cervical cancer in a given year) and non-decedents (those who have cervical cancer in a given year but do not die). By applying the suffering prevalence and duration estimates to the number of decedents, non-decedents, and family caregivers in 2017, we were able to estimate their palliative care needs.
Results: There is a high prevalence among decedents of moderate or severe pain (84%), vaginal discharge (66%), vaginal bleeding (61%), or loss of faith (31%). Among both decedents and non-decedents, there is a high prevalence of clinically significant anxiety (63% and 50% respectively), depressed mood (52% and 38%), and sexual dysfunction (87% and 83%). Moderate or severe financial distress is prevalent among decedents, non-decedents, and family caregivers (84%, 74%, and 66% respectively). Over 40% of decedents and non-decedents are abandoned by their intimate partners. Most patients experience a combination of physical, psychological, social, or spiritual suffering. In total, 258,649 decedents and 2,558,857 non-decedents needed palliative care in 2017, approximately 85% of whom were in low- and middle-income countries.
Conclusion: Among women with advanced cervical cancer, suffering is highly prevalent and often severe and multi-faceted.

Abstract number: G-19
Abstract type: Poster

The Effect of Culture, Socioeconomic Status and Health Literacy on Public Perceptions of Palliative Care and the Impact on Access: A Systematic Review and Critical Interpretive Synthesis

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Background: Public misperceptions about palliative care may contribute to poor palliative care access in different settings globally.
Aims: To better understand public perceptions of palliative care and influences on them.
Methods: Systematic review with critical interpretive synthesis (CIS). Non-MeSH terms for palliative care and perceptions were used to identify quantitative, qualitative, and mixed-methods studies in MEDLINE, EMBASE, PsycINFO, CINAHL and, Web of Science Social Science Citations Index Expanded and Conference Proceedings Citation Index (1 Jan 2002 to 31 May 2020). Search results were screened against *a priori* inclusion criteria, data extracted and quality appraised by two independent researchers. Data were combined and analysed using CIS.
Results: 48/33985 studies from Europe, North America, Asia and Australasia were included (32 quantitative, 9 qualitative, 7 mixed methods), representing 32585 members of the public (aged 18-101; 54% women). Knowledge of palliative care is poor, especially for men, younger people, ethnic minorities and marginalised groups (demographics that mirror cultural differences, lower socioeconomic position and poor health literacy). Public perceptions vary within and between countries. A perception consistent around the world is, palliative care *is* "death" or "giving up"; though to some it is comfort care allowing a natural death. Experience of palliative care improves understanding, when it is seen as good care offered by compassionate people, albeit still to be avoided until unavoidable with a consequence that access to palliative care is at best, delayed.
Conclusion: Public understanding of palliative care is poor and it is often seen as death. (Mis)perceptions discourage access and are influenced by culture, socioeconomic position, and health literacy. Alongside integration of palliative care services, to improve access countries need to increase exposure to and education about palliative care considering these factors.

H Posters Psychological, Social and Spiritual Care

Abstract number: H-01
Abstract type: Poster

'The Room where it Happens': An Exploration of Personalised Virtual Reality (VR) - Bringing the Home to the Hospice during the COVID-19 Pandemic

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Background: Virtual Reality (VR) provides a way to transport someone to a different place and time.

Harlington Hospice has explored using VR with inpatients, including the oldest old. It has taken patients back to the street where they grew up or to visit tropical places on their bucket list. These experiences have been uplifting and the feedback has provoked further exploration of the use of VR during the pandemic.

Goals: The primary goal is to provide personalised VR content to inpatients.

COVID-19 has meant that patients, even in a hospice, have had to endure visiting restrictions – the antithesis of palliative care and often heart-breaking. The use of VR cannot replace a loved one sitting at the bedside, but the VR experience might provide spiritual comfort.

A secondary goal is to provide family with a means to stay connected with the patient. Empowering people to attend virtually may reduce guilt and grief caused by separation.

Design and Proposal: A 360 (GoPro) camera is provided to family or friends of inpatients. They take the camera home and the recorded content of home life is then played in VR to the patient, immersing the patient back into family life. This is very different from just watching a video.

Family and friends can tell stories and say their goodbyes, and the patient will feel fully part of the conversation when they use the headset.

Discussion: After publishing "How Virtual Reality helped Pam (aged 86) travel to the Galapagos Islands!" in the Hospice newsletter, 2 VR headsets have been donated plus a grant to buy the GoPro camera. Policies covering data collection, consent, confidentiality and headset care are in place.

Written instructions are provided with the camera and a number for phone assistance. Once the personalised VR content has been created, it is transferred onto the VR headset.

Qualitative experience and impact themes will be collected.

We are not aware of VR being used in this way by any other provider.

Abstract number: H-02
Abstract type: Poster

RELAX: RELationship between AnXiety and Palliative Care. Anxiety VAS and NRS Study - Final Results

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Background: In view of the high prevalence of anxiety in the palliative care setting and the fact that it is regularly underestimated by healthcare professionals, it is important to develop simplified tools in order to facilitate evaluation and follow-up of anxiety. Visual analogue scale (VAS) and numerical rating scale (NRS) are validated tools to evaluate pain. These tools have not been validated for the evaluation of anxiety in palliative care.

Aim: To study the correlation between two brief scales (Anxiety VAS and NRS) and the State-Trait Anxiety Inventory-State (STAI-S) (reference 20-question scale) to evaluate anxiety in palliative care patients.

Methods: Single-centre, prospective observational study validated by an Ethics Committee. All palliative care patients followed by the palliative team of a French university hospital were eligible for inclusion. Each patient filled in a STAI-S and evaluated his/her perceived anxiety by an NRS and a VAS. All treatments taken by the patient were also recorded. A Pearson's correlation test between the two scales and ROC curve analysis were performed to determine possible diagnostic cut-offs.

Results: 186 patients were included (90% had cancer). 20.4% of patients presented severe or very severe anxiety according to their STAI-S score. But 68% were currently receiving anxiolytic treatment. The correlations for the different scales were respectively 0.62 NRS/STAI-S, 0.70 VAS/STAI-S. The discrimination of the NRS and the VAS was good with an area under the ROC curve of 0.81 and 0.88 respectively. A cut-off of 5 (for the NRS) and 50 mm (for the VAS) achieved a sensitivity of 89% to detect severe or very severe anxiety according to ROC curve analyses, with a specificity of 60% and 70% respectively.

Conclusion: We therefore have a low prevalence of anxiety compared to other studies but a significant prescription of anxiolytics. Cut-offs of 5 for the NRS and 50 mm for the VAS presented excellent sensitivity to detect anxiety.

Abstract number: H-03
Abstract type: Poster

Coping Strategies of Patients with Advanced Lung or Colorectal Cancer over Time

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Background: Insight into how coping of patients with advanced disease might change over time is lacking.

Aim: To examine coping strategies of patients with advanced cancer over time and associated factors.

Methods: In the ACTION cluster-randomized trial the intervention group was offered advance care planning. 1,117 patients (mean age 66 years) with lung or colorectal cancer from 6 European countries (Belgium, Denmark, Italy, the Netherlands, Slovenia and the United Kingdom) completed questionnaires at baseline, 12 and 20 weeks. Measures included Denial, Acceptance, and Problem-focused coping (COPE, Brief COPE inventory; scores ranged 4 – 16 per scale). The minimal clinically important difference was operationalized as half a standard deviation. Linear mixed models were used.

Results: Coping did not differ over time between patients in the intervention and the control groups. We found statistically significant changes in coping strategies over time and significant differences between subgroups, but these were small and not clinically relevant. At baseline, patients scored low on Denial (6.7), which did not change over time ($p=0.432$). High baseline scores on Acceptance decreased from 12.8 to 12.5 ($p=0.008$). High baseline scores on Problem-Focused coping decreased from 12.2 to 12.0 ($p=0.009$). Overall, older patients' Denial scores were higher ($p<0.001$) and Acceptance scores were lower ($p=0.006$) than those of younger patients. At baseline, Denial scores were higher for Denmark (7.7), Italy (7.4) and Slovenia (7.2) than for other countries, and these differences persisted over time. Acceptance scores were lower for Belgium, whereas they were higher for the United Kingdom.

Conclusion: We observed significant but small changes in coping strategies of patients with advanced cancer over time and small differences between subgroups. These findings indicate that the overall use of coping strategies in this population seems to be rather stable.

Abstract number: H-04
Abstract type: Poster

Recommendations for Psychosocial Support Measures for Parent–adult Child Dyads at the End of Life: A German Delphi Study

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Background: The availability of psychosocial support measures has a great impact on the quality of life and experienced burden of terminally ill patients and their family caregivers. Interventions focusing on the specific needs of (1) terminally ill adult children and their parents and (2) terminally ill parents and their adult children are lacking.

Aims: A Delphi study was conducted to consent recommendations for dyadic psychosocial support measures in Germany.

Methods: The study is part of the Dy@EoL project (2017-20). Recommendations were drafted on the basis of qualitative interviews, conducted in a previous project phase with patients and family caregivers of both dyads. Palliative and hospice care representatives were asked to rate relevance and feasibility of 21 recommendations on 4-point Likert-type scales and provide suggestions for improvement (06-07/2020). Consensus on recommendations was defined as being achieved when the percentage of items scoring 1 (strongly agree) or 2 (somewhat agree) regarding relevance as well as feasibility was ⩾80%.

Results: Delphi round 1 was completed by 43% (n=33/77) of the invited experts. The participation rate in round 2 was 82% (n=27/33). Consensus was reached in round 1 on all recommendations of the core theme “support and relief” (e.g. on exploring patients’ needs/caregivers’ resources). Two recommendations could not be consented in round 1: (i) panellists saw the limited remaining time in end-of-life situations as hindering an intervention on biography work; (ii) panellists missed an explanation on offering a discussion of family communication patterns only when communication is perceived as burdensome. Consensus for all 21 initially presented recommendations was achieved after two rounds.

Conclusion: The Delphi-consented recommendations provide the first advice for manifold dyadic psychosocial intervention measures for parents and adult children at the end of life.

Funding: German Federal Ministry of Education and Research

Abstract number: H-07
Abstract type: Poster

What Are Barriers or Facilitators for Multidimensional Symptom Management in Palliative Care? A Focus Group Study among Patient Representatives and Clinicians

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Background: Patients with a life-limiting illness usually experience multiple multidimensional symptoms. Although the importance of a holistic approach to symptom burden is widely acknowledged, such is difficult to integrate in daily practice.

Aim: To identify barriers and facilitators for multidimensional symptom management in palliative care.

Methods: Six focus groups with various groups of stakeholders were conducted:

1) patient representatives;
2) community nurses;
3) hospital nurses;
4) general practitioners;
5) hospital physicians;
6) palliative care specialists.

Audiotapes were transcribed verbatim and thematically analysed.

Results: Fifty-three stakeholders (6-13 per group) participated. Facilitators and barriers concerned the assessment of symptoms and needs, initiating interventions and referrals, multidisciplinary collaboration, healthcare organization, patient/family-clinician interaction and timing of care. Most barriers and facilitators specifically concerned the management of physical symptoms or the overall symptom burden. Barriers that particularly hinder adequate management of psychological, social and spiritual needs mostly concerned the assessment of those needs. Such assessment is hindered by: clinicians and patients focussing on physical symptoms, clinicians lacking the skills to address non-physical needs and patients avoiding full disclosure of their complaints or having coping issues. A good patient-clinician relationship and use of symptom assessment scales are facilitating for multidimensional assessment. In addition, barriers to adequate interventions and referrals for non-physical needs were clinicians tending to focus on pharmacological interventions and unfamiliarity with referrals to non-medical clinicians, like chaplains.

Discussion: To improve multidimensional symptom management, it is paramount to address the barriers and facilitators that patients and clinicians experience in assessing non-physical dimensions of palliative care.

Abstract number: H-08
Abstract type: Poster

What Is the Understanding of Dignity within Palliative Care in Middle Eastern Countries? An Integrative Review

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Background: Patients with terminal or advanced chronic diseases may experience loss of personal dignity due to the heavy burden of psychological and physical symptoms. Palliative care aims at upholding the sense of dignity and worth of patients with serious illnesses. Little is known on how dignity is perceived or preserved in Middle Eastern countries within palliative care.

The aim of this review is to a) identify and synthesize research on the concept of dignity in patients with palliative care needs in the Middle East; b) examine the findings against the understanding of dignity in the western literature.

Method: An Integrative review was adopted. Four databases, CINAHL, PubMed, PsychInfo, and Embase were searched until December 2020. To enhance the search sensitivity three online journals were hand searched and forward citation tracking was employed. Two researchers

independently scanned the title and abstracts against the inclusion criteria, extracted data, and assessed quality using Hawker's appraisal tool.
Results: Of 5113 retrieved papers, 16 papers were included for synthesis. Most were published in Iran. The following seven themes were generated.

1. Maintaining physical privacy and informational secrecy
2. Gentle communication maintaining hope
3. Abundance and affordability of resources
4. Presence of the family as a key support system
5. Physical fitness that maintains independence
6. Reliable health care
7. Social justice ensuring equitable care

Conclusion: The findings are in general lines compatible with the western understanding of dignity where physical independence, social support, and personal outlook make up the sense of dignity. However, sociopolitical realities and cultural values such as maintaining hope, financial stability, and accessible health services are regarded as essential to preserving dignity.
No funding was received for this research.

Abstract number: H-10
Abstract type: Poster

Confronting Finitude from the Perspective of people Aged 80 and over or with a Life-limiting Disease: A Qualitative Study

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Background: Being confronted with the finitude of life may enable to accept dying and consequently increase well-being. To date, there is a lack of studies exploring perspectives of people aged 80 and over or with a life-limiting disease on being confronted with one's finitude, especially regarding individual coping strategies and experiential learning.
Aim: Exploring experiences and wishes of being confronted with one's own finitude of people aged 80 and over and people with a life-limiting disease.
Methods: 16 semi-structured interviews were conducted face-to-face with people aged 80 and over (n=11) and with a life-limiting disease (n=5) so far. Participants were sampled purposefully. Interviews were audio-recorded, transcribed verbatim and analyzed using the thematic analysis approach of Braun and Clarke. Data collection is still in progress.
Results: The experience of being confronted with the finitude of life was reported in terms of preparing the end of life (e.g. advance directives), acquisition of knowledge, experiential learning (e.g. end of life care) and varying forms of life reflection. These different approaches of confronting finitude were perceived as relieving anxiety and therefore interrelated with positive feelings. Some participants expressed an avoiding attitude towards dying and the wish to focus on the beautiful things in life. However, confrontation was considered as important, especially as reaction to the concern of not being prepared. The majority emphasized fearing the sense of being a burden to others as well as the wish to leave a lasting legacy. The opportunity to talk about death-related topics and to reflect on the life lived was rated as preferable.
Conclusion: To meet the psychological needs, low-threshold settings giving the opportunity to review and reflect life, discuss death-related topics and thereby strengthen a sense of meaning should be provided.

Abstract number: H-11
Abstract type: Poster

Spiritual Care Training with Healthcare Professionals and Students: A Systematic Review of the Literature

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Background: It has been well established that spirituality plays an important role in healthcare. However, many healthcare professionals feel ill-equipped to deliver spiritual care. To address this need, a range of spiritual care training programs have been developed.
Aims: To identify spiritual care training programs for healthcare professionals or healthcare students, and to investigate program content, teaching methods, key outcomes, and identified challenges and facilitators.
Methods: A mixed-methods systematic review was conducted. The search terms ('religio*' OR 'spiritual*' OR 'existenti*') were combined with ('educat*' OR 'train*' OR 'curricul*' OR 'program*'), AND ('care' OR 'therap*' OR 'treatment' OR 'competenc*'). The search terms were entered into the following data bases: PsycINFO, Medline, Cinahl and Web of Science. Findings were restricted to peer-reviewed studies published in English between January 2010 and February 2020.
Results: Fifty-five studies were identified. The quality of studies was mixed. Few studies included control groups, and follow-up data was often not collected. Programs encompassed a range of content and teaching methods. Increased levels of competency were reported across intrapersonal spirituality, interpersonal spirituality, and spiritual assessment and interventions. Identified barriers included competing healthcare priorities, negative perceptions of spirituality and spiritual care, resistance towards focusing on one's own spirituality, staff feeling inadequate, and the need for ongoing training. Facilitators included the involvement of chaplains, opportunities for practice and reflection, application of spiritual care assessment tools, online training, and managerial support.
Conclusion/ discussion: Positive outcomes following spiritual care training were reported. Further research is needed to identify patient-related outcomes of staff training, and to examine how training outcomes can be maintained over time.

Abstract number: H-12
Abstract type: Poster

HOPEVOL: Hospice Patients Admitted to the Different Types of Hospice Facilities in the Netherlands

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Background: Hospice care in the Netherlands is provided in three different types of hospice facilities: Volunteer-Driven Hospices (VD), Hospice Unit Nursing Homes (HU), and Stand Alone Hospices (SA). The organizational structure ranges from care provided by trained volunteers in VD to care provided by multi professional teams in SA and HU.
Aims: Describe and compare patients and patient's needs at admission in hospices.

Methods: A retrospective study using patient records. Adult hospice inpatients deceased in 2017-2018 were enrolled. A random sample of 17 hospices per hospice type was drawn. Main outcome were patient's needs in the four dimensions. Physical symptoms and performance status were collected, as were psychological problems concerning cognition and emotion, social concerns involving caregivers / family, and existential needs. Potential differences between the patients in the different types of hospices were tested with either a chi-squared or a Kruskal-Wallis test.
Results: At this moment 712 patients are included from 45 hospices (13 VD, 15 HU, 17 SA), median age 77, IQR [69-85], 78% with cancer, and 47% were $>$50% of the day bedridden. At admission, all patients perceived physical needs. Psychological needs were experienced by 37%, 34%, and 36% patients (p=.77) and social needs by 53%, 62% and 53% (p=.10) in VD, HU and SA resp. Existential needs differed between patients per type of hospice: 23%, 18% and 30% (p=.005) in VD, HU and SA resp. Of all patients, 29% experienced problems in three and 5% in four dimensions (not different between types of hospices).
Conclusion The comparability of patients between hospice types shows that a patient's needs do not seem decisive for the choice of hospice in the Netherlands.
Discussion: Between hospices, patient records have different formats, varying from comprehensive chronicles to separated files per type of professional. Future research will focus on effects of type of registration for retrospective studies.

Abstract number: H-13
Abstract type: Poster

Anxiety and Depression in Palliative Care - Issues Experienced by Health Care Professionals in the Netherlands: Results of an Online Survey

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Background: Anxiety and depression are common problems in patients with a life-threatening illness and are known to have a negative impact on quality of life. To improve clinical management of anxiety and depression in palliative care, the Dutch guidelines are currently revised by a multidisciplinary committee of professionals. The aim of the guideline is to provide practical and evidence based guidance.
Aims: The first step of revising this guideline is to identify relevant needs and issues in the management of anxiety and depression in palliative care, as experienced by health care professionals in the Netherlands.
Methods (design, data collection, analysis): The guideline committee designed a 12 item survey based on their professional experience. An online survey was sent to relevant (professional) associations, posted on social media and distributed in the professional networks of the members of the guideline committee. Each item could be rated on a 3 point scale, from not a relevant problem to a very relevant problem.
Results: A total of 210 health care professionals completed the survey. They consisted of nurses or nurse practitioners (29%), medical specialists (29%), chaplains/spiritual care takers (18%), and other (25%). The issues that were identified as most relevant were 1) Cultural differences in expression of anxiety and depression (76%); 2) Overlapping of anxiety and depression with symptoms related to somatic or cognitive suffering (76%); 3) Organisation of care (66%); 4) Recognizing risk factors or causes (64%) ; 5) Prevention (62%); and 6) Differential diagnosis (58%).
The priorities of issues slightly differed between disciplines.
Conclusion / discussion: Health care professionals identified problems in the management of anxiety and depression in patients with a life-threatening illness. These issues will be addressed in the revised guideline in order to optimize treatment for these patients.
Source of funding: ZonMw

Abstract number: H-14
Abstract type: Poster

Spiritual Well-being, Attitude, Involvement, Perceptions and Competencies: Measuring the Self-perception of Nursing Students during 2018, 2019 and the First Wave of COVID-19 in 2020

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Background: Developing spirituality and spiritual care competencies in nursing students is an important task. In German-speaking countries, research investigating spiritual care in nursing teaching and nursing practice is limited.
Aims: The aim of this study was to measure nursing students' perceptions of their spiritual care competencies, care attitudes, involvement, perception and well-being.
Methods: Three groups of second-year undergraduate nursing students in the years 2018, 2019 and 2020 participated in a cross-sectional study using validated scales to measure students' spiritual well-being (JAREL), spiritual care attitudes and involvement (SAIL), spirituality and spiritual care perceptions (SSCRS), and competencies (SCCS).
Results: Nursing students ($N = 191$) show a high level of spiritual attitude and involvement. The groups attained similar scores on the SSCRS, but the group of 2020 achieved the highest score, indicating a broader view of spirituality. This group also scored highest on the SCCS, which shows a higher self-perceived competence in delivering spiritual care. At the same time, the 2020 group reported significantly low spiritual well-being scores. Students rated their competencies in delivering spiritual care as high. This may be negatively affected if their spiritual well-being remains low.
Conclusions: Further investigation is needed to clarify how to tackle this shortcoming in educational training.

Abstract number: H-15
Abstract type: Poster

Testing Terror Management Theory in Advanced Cancer

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Background: Terror management theory (TMT) has been applied to explain how healthy individuals manage the awareness of mortality and resulting death anxiety, but whether it explains how individuals who are actually facing impending mortality manage death anxiety has not been previously evaluated.
Aims: We assessed the effect of the distal defenses of attachment security, self-esteem and the sense of meaning postulated by TMT to buffer the relationship between physical impairment and death anxiety in advanced cancer.
Methods: Patients with advanced cancer participating in a psychotherapy trial in Toronto, Canada (N=398 at baseline) completed measures of physical impairment, attachment security, sense of meaning, self-esteem, and death anxiety. Using structural equation modelling, we compared groups with collectively weak, partial, or strong distal defenses (N=204) on the physical impairment–death anxiety relationship at three time periods.

Results: At baseline, the defense groups did not differ in the physical impairment–death anxiety relationship (β=.39 for all groups; CFI=.96). At three months, all three groups differed significantly on the physical impairment–death anxiety relationship in the hypothesized direction (β=-.06, .48, and .83 for strong, partial, and weak defense groups, respectively; CFI=.93). At six months, the strong defense group demonstrated a significantly weaker physical impairment–death anxiety relationship than both the partial and weak defense groups (β=.23, .81, and .81, respectively; CFI=.98).

Conclusion: Individuals with advanced cancer who have greater attachment security, sense of meaning, and self-esteem are relatively protected from death anxiety with disease progression, compared to those weaker in these domains. These findings support TMT and may help to identify individuals at risk and to examine the mechanism of effect of psychotherapeutic interventions to reduce death anxiety.

Abstract number: H-16
Abstract type: Poster

Depression Care in Very Poor Prognosis Setting is Complex and Challenging – Perceptions, Key Barriers and Potential Solutions by Australasian Palliative Physicians and Psychiatrists (Focus Group)

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Background: Depression is common and debilitating in individuals with advanced life-limiting illnesses and very poor prognoses (range of days to weeks). However, depression screening, assessment and management in this setting may be very challenging. The perception of Australasian palliative physicians and psychiatrists, including perceived barriers to optimal care and potential solutions, has not been studied.

Aim: To determine the perceptions of Australasian palliative care physicians and psychiatrists in screening, assessing and managing depression in patients with very poor prognoses, exploring key barriers to optimal care and potential solutions.

Methods: Three focus groups involving fellows and trainees recruited online from Australian and New Zealand Society of Palliative Medicine (ANZSPM) (n=11) and Royal Australian and New Zealand College of Psychiatrists (RANZCP) (n=4) were conducted in Nov-Dec 2020. Qualitative data was independently coded, categorised and discussed by two investigators using NVivo 12.

Results: Key themes included: complexity of care; clinician concerns (e.g. stigma, over-burdening patients); non-uniformity of approaches; lack of evidence to guide practice; inadequate clinician training; and the lack of resources and collaboration between palliative care and mental health services. Postulated solutions: improving clinical training, health service delivery and research through better collaboration between the palliative care and mental health services.

Conclusion/Discussion: Australasian palliative physicians and psychiatrists perceived screening, assessing and managing depression in people with very poor prognose to be complex and challenging. Strategies to improve resourcing and collaboration between palliative care and mental health services with integrated training, service delivery and research may be helpful.

Abstract number: H-17
Abstract type: Poster

Psychosocial and Spiritual Intervention Strategies in Palliative Care: Evidence from a Cohort Study

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Interventions in palliative care (PC) on the psychological, social and spiritual domains encompass the support on the adaptation process of disease or proximity of death, as well as of the overall suffering manifested by the patients or family and ensures an answer to the psychosocial and spiritual needs. Analyse, describe and characterize the psychosocial and spiritual intervention of a psychosocial care team (PCT) on patients and relatives.

Exploratory retrospective descriptive study based on the analysis of clinical records on the psychosocial support of patients and relatives followed by a PCT, from admission to discharge.

A total of 385 patients were identified, 51.4% male (n = 198), median age (71.3 years), 89.4% with main oncology diagnosis; and 440 relatives, 71.1% female, with a median age of 54.5 years. The construction of the categories of analysis is based on the guidelines of psychological intervention in PC of the Portuguese Psychology College. For patients and relatives, 3 major categories and 28 subcategories were identified. As most prevalent we point out: "active listening", "emotional support and facilitation" and "emotional expression facilitation" for patients (75.8/70.1/69.6%). For relatives, "active listening", "emotional support and facilitation", "facilitation of emotional expression" stand out (98.9/85.9/81.8%). Note that "family assertiveness and communication training", "conflict management and negotiation", are the least frequent interventions in the patient group (15,8/13,3%) and for relatives are "promoting dignity in the family", "promoting autonomy" (13.6/11.1%). The results demonstrate the role of psychosocial and spiritual intervention in patients and relatives in PC. The bond established in the empathic relationship validates the suffering of the other, have an impact on well-being and grief experience, allowing a greater humanization of the end-of-life process. Funding: none; No conflicts registered.

Abstract number: H-18
Abstract type: Poster

How the Introduction of Professional Artists in a Palliative Day Care Centre Affects its Caregivers, an Ethnographic Study

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Background: In the framework of 'whole patient care', there is a growing interest worldwide to engage professional artists in palliative care. To date, research has mainly focused on how artists influence the health and well-being of end users through their practice.

Aim: How the presence of professional artists affects the caregivers, present in the care facility where they work, remains under-researched. This is therefore the focus of our study.

Method: We conducted ethnographic research in a Belgian palliative and supportive day care centre that receives 15-25 'guests' (as end users are called) daily with a chronic, life-threatening condition. A three-year (2016-19) multidisciplinary arts program invited ten professional artists to develop a variety of activities at the centre. In addition to observations, both formal and informal interviews were conducted with the centre's staff, interns and volunteers during the last eight months of the arts program.

Results: The findings showed a gap between respondents who had participated in the artistic activities and those who had not. The former spoke mostly positively, mentioning a positive effect of the activities on their personal well-being and indicating that their participation had improved their relationships with guests. The latter mainly mentioned feelings of irritation and disturbance, labelling the activities as 'too experimental', 'incomprehensible' and sometimes 'shocking'. Some of them, however, described an evolution over time: their appreciation of the activities increased when they noticed that they were appreciated by the guests.

Conclusion: It is important to inform the caregivers about how art activities affect the guests. Active participation of caregivers in the art activities should be encouraged, as it can offer them an embodied understanding of the activities and contribute to both their own well-being and better relationships with the guests.

Abstract number: H-19
Abstract type: Poster

Why Is the Social Worker Asking me about Code Status? A Description of Palliative Social Work Interventions

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Background: Palliative care social workers play a critical role in helping hospitalized patients and their families navigate the illness experience. They ease the social and emotional burdens associated with illness, facilitate family meetings and do a variety of other interventions. This study examines palliative care social work interventions at an urban academic center located in Washington D.C.

Aims: This study aims to measure the discrete activities performed by palliative social workers within an interdisciplinary palliative care team at one hospital and the potential influence of those activities on patient care paths and outcomes.

Methods: 3 social workers recorded their specific interventions for the period from October 19, 2020 through December 31, 2020. Researchers matched this time study data with demographic and clinical information obtained from patient electronic medical records. Data was then analyzed using descriptive statistics.

Results: Over this period, social workers made 833 patient visits and performed 2,405 interventions (2.9 interventions per visit) for 329 patients and their families. Social work interventions involved advanced care planning (31%), with 22% of time spent on care coordination and 12% on family outreach and support. The majority of consultations came from the ICU (45.1%) followed by medical/surgical units (37.1%). Patients in the study had an average age of 65.1 years with the majority admitted for cardiovascular disease (22.2%), followed by infection (19.8%).

Conclusion/ discussion: This study exampled specific social work interventions beyond "providing support" and demonstrates the impact of having trained palliative social workers. The study was conducted at a single academic center with a mature, high volume palliative care service and results may not be easily replicable.

Abstract number: H-20
Abstract type: Poster

Double Awareness in Advanced Cancer: Preliminary Psychometric Evaluation of a Novel Self-report Measure

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Background: Individuals with advanced cancer face the paradoxical task of remaining meaningfully engaged in life, while also preparing for end-of-life. Sustaining this duality, referred to as "double awareness," may reflect optimal psychological adaptation but there has been no validated measure.

Aim: To evaluate the psychometric properties of a newly developed measure of double awareness, the Double Awareness Scale (DAS).

Methods: 200 patients with advanced cancer will be recruited from an outpatient palliative care clinic. Self-administered questionnaires will assess death anxiety, depression, symptom burden, attachment security, spirituality, quality of life, and double awareness. Exploratory factor analysis will assess item loading of the DAS onto factors of life engagement and death contemplation. Tests of construct validity and internal consistency will also be performed.

Results: Preliminary results ($n = 50$) demonstrate relatively high levels of life engagement and death contemplation: 69.61 (range = 7-88; SD = 15.97) and 48.87 (range = 13-72; SD = 13.02), respectively. Life engagement was correlated negatively with depression ($r = -.394$; $p < 0.01$), attachment anxiety ($r = -.528$; $p < 0.01$) and psychological symptoms ($r = -.487$; $p < 0.01$), and positively with quality of life ($r = .360$; $p < 0.05$), relationship with healthcare providers ($r = .497$; $p < 0.01$), life completion ($r = .598$; $p < 0.01$), and spiritual well-being ($r = .377$; $p < 0.05$). Death contemplation was correlated negatively with attachment anxiety ($r = -.294$; $p < 0.05$) and preparation for end-of-life ($r = -.376$; $p < 0.05$), and positively with life completion ($r = .336$; $p < 0.05$), and spiritual well-being ($r = .459$; $p < 0.01$).

Conclusion/ discussion: The results of this preliminary psychometric evaluation of the DAS are encouraging regarding its validity. Full testing of its validity and reliability will be conducted after collection of the complete dataset.

Abstract number: H-21
Abstract type: Poster

"Most of us Don't Feel Like we're Dying." Exploring the Relevance and Role of Advance Care Planning for People Severely Affected by Multiple Sclerosis: A Qualitative Interview Study

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Background / Aims: Little is known about how people severely affected by multiple sclerosis (PwMS) and their families comprehend advance care planning (ACP) and its relevance and role in their lives. This qualitative study aimed to understand what a successful ACP experience might resemble for PwMS and their families.

Methods: Twenty-five PwMS and 17 family members of PwMS consented to take part in either one-to-one (n=21) or PwMS-family member dyad (n=10) interviews between June 2019 and March 2020. Interviews were audio-recorded (mean duration 76 minutes) and transcribed verbatim. Data were analysed using the framework approach.

Results: While end-of-life planning was not viewed as relevant to participants, more than one-third of PwMS in the study had formally engaged in ACP, most commonly making a lasting power of attorney for health and welfare (LPA). Motivating factors for making an LPA included concerns about progressive loss of cognitive capacity and/or loss of mental capacity during acute illness episodes associated with MS complications (e.g., urosepsis, aspiration pneumonia). PwMS had appointed family members as their proxy decision-makers and had authorised them (rather than health care professionals) to refuse or consent to life-sustaining treatment on their behalf. The study identified several barriers to engagement in ACP including uncertainty relating to the MS illness trajectory, negative experiences of previous ACP discussions with clinicians, lack of information about the transition to a supportive care pathway, and prioritisation of symptom management, rehabilitation needs and quality of life issues.

Conclusion: These findings support the need for provision of information about the potential benefits of making an LPA for PwMS and their families. Having an LPA represented a reassuring and flexible tool for PwMS who lost mental capacity, and their families, to ensure their wishes and preferences relating to health and care decisions be supported.

Abstract number: H-22
Abstract type: Poster

Analysis and Function of Silence in the Discourse of Patients at the End of Life

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Context: Our research focused on the cognitive-emotional work of patients at the end of life. After a thematic analysis and an idiographic reading, we also took interest in the silence in the patients' discourse. Indeed, at the end of life, silence occupies a predominant place both in the patients' discourse and in the therapeutical alliance.

Objective: The goal was to study the function and place of silence in their speech.

Method: The patients were in a symptomatic palliative phase and hospitalised in an oncology unit. A semi-structured interview conducted by a psychologist was carried out in order to collect their experiences. After transcribing the interviews, each extract containing silences was analysed. We based our analysis on the work of Levitt (2001) to classify the silences in three categories: productive, obstructive and neutral silences.

Results: The nine patients included were women with an average age of 71 years old [60-90]. We gathered 28 extracts including a time of silence. It emerged that twenty-five of these silences are considered to be productive because they describe emotional silences (n=17) and expressive silences (n=8). The other three silences are obstructive, indicating a disengagement from speech. Also, we noticed that emotional silences appeared when patients talk about their illness, family and end of life. Expressive silences appeared when patients talked about the end of life, theirs needs and resources. Finally, disengaged silences are evenly distributed during exchanges around the disease, reminiscence and also serve as defense such as cognitive avoidance.

Conclusion/Discussion: These initial results shed light on the function of silence at the end of life. They demonstrate that the silences are very diverse. It's important for the therapist to take them into account in order to improve the therapeutical alliance and the quality of the support.

Abstract number: H-23
Abstract type: Poster

The Meaning of Art in Palliative Care from the End Users' Perspective

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Background: In the framework of 'whole patient care', there is a growing interest worldwide to engage professional artists in palliative care. Studies concerning such art initiatives mainly offer the artist's perspective on how their practice (positively) impacts the participants. Our study presents the voice of the end users.

Aim: We investigate how end users of a palliative care centre experience and value art activities.

Method: We conducted ethnographic research at a Belgian palliative and supportive day care centre that receives 15-25 'guests' (as patients are called) with a chronic, life-threatening condition daily. A three-year (2016-19) multidisciplinary arts program invited ten professional artists to develop a variety of activities at the centre. Our research design included observations as well as informal interviews with 16 guests during the last eight months of the art project.

Results: Guests reported that their participation in these art activities had a positive influence on their personal and social well-being. The activities provided distraction and put them in a better mood. In providing a topic to talk about, they also contributed to better relationships with other residents and care providers, as well as with their personal network outside the care centre. Respondents also noted a cultural and artistic value: the activities offered them new learning experiences and stimulated their imagination and senses. A minority of the respondents mentioned negative feelings when activities adversely affected their health and well-being, when they perceived activities as 'incomprehensible' or in case of logistic hassle.

Conclusion: Arts activities in palliative care can be valuable for the end users. However, attention should be paid to possible negative repercussions on their health and well-being. Participants should be informed in advance of the nature and purpose of the art activities. Practical hassle should be avoided as much as possible.

Abstract number: H-24
Abstract type: Poster

Improving Frontline Healthcare Workers Wellbeing during the COVID-19 Pandemic through Creative Writing; A Pilot Study and a Unique Collaboration between The Open University and an Acute Hospital Trust

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Aim: The COVID-19 pandemic has resulted in healthcare workers (HCW) with a wide breadth of previous experience caring for a vast number of dying patients; including many with distressing symptoms. Recent rapid review of the evidence has highlighted that HCWs responding to the pandemic are under significant physical and psychological stressors which may lead to ongoing mental health problems; with research yet to illicit the most effective way to provide support. Creative writing for wellbeing has previously been used to support war veterans and so a pilot study was developed to investigate if this method could potentially improve wellbeing for HCWs.

Methods: All clinical staff at an acute hospital were invited to participate via e-mail. Written informed consent was sought from all participants and background data gathered including their role and specialty. All participants were provided with a Creative Writing for wellbeing workbook and invited to attend three virtual workshops, over 3 months. Participants were encouraged to continue therapeutic creative writing between sessions. After each workshop, participants were asked to anonymously complete a survey, ranking on a Likert scale multiple aspects relating to their perceived usefulness of the sessions in improving wellbeing.

Results: 14 frontline hospital HCWs participated, from a range of specialties; included 7 nurses, 4 doctors and 2 other HCWs. Feedback was overwhelmingly positive with 100% of survey respondents agreeing that they had found it to be a positive experience and that they felt enabled to use the techniques learned for the future.

Conclusion: This pilot shows creative writing workshops to be a feasible and welcome intervention, in providing support to healthcare workers facing the COVID-19 pandemic. Although numbers are small, a positive impact was felt by those who participated. The next step is a multi-site study to gather evidence of effectiveness of this intervention on a larger scale.

Abstract number: H-25
Abstract type: Poster

The Impact of Self-reported Distress on Healthcare Services Utilisation in Patients Diagnosed with Breast and Gynaecological Cancer

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Background: Patients with cancer often have unmet needs during their cancer journey, putting them at risk for distress which is associated with reduced quality of life, poorer health outcomes, and possibly higher mortality. We hypothesised that patients reporting high distress would be associated with additional healthcare services utilisation including Emergency Department (ED) visits and hospitalisations.
Aim: This study aimed to investigate the association between distress and healthcare services utilisation in a cohort of breast and gynaecological cancer patients across different survivorship stages.
Methods: This was a retrospective cohort study of patients who visited an outpatient oncology centre between 16 September 2019 and 31 July 2020. Distress was evaluated using the self-reported Distress Thermometer and Problem List (DTPL), with DTPL score $\geqslant 4$ signifying high distress. Demographics and clinical data were extracted from the electronic medical records. Multivariable logistic regression was used to estimate the odds ratio of ED visits and hospitalisations within 30 days of the DTPL screening, adjusted for co-variates.
Results: Of the 1386 patients included in the analysis, 510 (36.8%) reported high distress on their first DTPL. Patients with high distress were associated with higher odds of ED visits (adjusted OR=2.25, 95% CI:1.14-4.42, p=0.019) and hospitalisations (adjusted OR=2.11, 95% CI: 1.29-3.49 p=0.004).
Conclusion: This study found that self-reported distress was associated with higher odds of increased healthcare services utilisation in terms of ED visits and hospitalisations in patients with breast and gynaecological cancer. Identifying the aetiology behind the association can help to guide appropriate interventions in the framework of managing distress, to reduce unplanned healthcare services utilisation and eventually healthcare costs.

Abstract number: H-26
Abstract type: Poster

Self-awareness and Self-care as a Way to Cope with Suffering and Death: A Participatory Action-research in Palliative Care

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Aim: Palliative care is an emotionally and spiritually highly demanding setting of care. Research on how to train on self-awareness, self-care and inner life of the healthcare professionals, according to available resources and local context, is still needed. We examined the effects implied in a training on self-awareness structured as an action-research for a Hospital Palliative Care Unit.
Methods: Action-research training experience for four physicians and two nurses in the setting of continuous medical education, based on qualitative data, comprehending self-assessments, field notes, group reflection sessions and satisfaction questionnaires. Thematic analysis of open-ended questions, researcher's field notes, oral and written feedback from trainers and participants on training outcomes and satisfaction questionnaires were used.
Results: The training course resulted in: 1) ameliorative adjustments of the program; 2) improved skills in self-awareness and sharing of perceived emotional and spiritual burden; practicing 'compassionate presence' with patients also in COVID Pandemic; shared language to address previously uncharted aspects of coping; 3) giving continuity to the skills learned: the language learned is translated into daily clinical practices through specific facilitation; 4) Staff Support Case for the emotional experience about the incoming year.
Conclusion: Coping with death and awareness are important predictors of quality of life, being positively related to Compassion Satisfaction. The core of this work was to encourage a meta-perspective in which the trainees developed greater perspicacity about their professional role in the working alliance, also recognizing the contribution of their personal preoccupations to impasse experienced with patients. The learned lesson from training course during pandemic was that being aware of compassionate presence during the short visits to isolated COVID-19 patients restored dignity and humanity.

Abstract number: H-27
Abstract type: Poster

Adapting ENABLE for Advanced Cancer Patients and their Caregivers in Singapore

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Background: ENABLE (Educate, Nurture, Advise, Before Life Ends) is a nurse coach-led, early palliative care model for patients with advanced cancer and their family caregivers. Content covered includes problem-solving, advance care planning, symptom management and self-care.
Aims: To evaluate the cultural acceptability of ENABLE among patients with advanced cancer and their caregivers in Singapore and identify modifications for an adapted ENABLE-SG model.
Methods: Qualitative formative evaluation in National Cancer Centre and Khoo Teck Puat Hospital, Singapore, involving patients (n=10), family caregivers (n=11) and healthcare professionals (n=10) who care for patients with advanced cancer. Semi-structured interviews were conducted to explore (i) the main needs and challenges facing individuals with advanced cancer and their family caregivers; (ii) patient involvement in healthcare decision making; and (iii) content and delivery of ENABLE.
Results: While physical needs were largely well met, participants expressed that psychosocial care was delivered too late in the illness trajectory. Healthcare decision making approaches varied from a patient-centred shared decision-making model to a family-centred model where patients may not know their cancer diagnosis and prognosis. The content was considered to be relevant, comprehensive and practical; financial assistance, adjustment to body image, and evaluation of complementary

therapy were also recommended. Face-to-face rather than telephone sessions were preferred to facilitate rapport building.

Conclusion: ENABLE was broadly acceptable with some modifications, including adjusting the content to ensure it can be delivered even if the patient is not fully aware of cancer diagnosis and delivering the first session face-to-face with flexibility for subsequent sessions.

Abstract number: H-28
Abstract type: Poster

„Hope Is the Motor for Change. . ." - Insights from Expert Interviews about Resilience, Sense of Coherence and Further Concepts in Palliative Care

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Background: In times of (pandemic) crisis, the term "resilience" receives increasing attention, even though it has not been defined precisely. The spectrum of related terms and concepts in the field of palliative care is large. Quality of life, dignity, meaning in life, sense of coherence or extensive dimensions of spirituality are just a few examples of why it is a challenge to sharpen the understanding of the term. In addition, a variety of interventions which may be related to resilience are discussed for seriously ill and dying patients, for their caregivers and for staff members.

Aims: The aim of this study is to examine the concept of resilience by relating it to concepts and interventions commonly used in palliative care and to identify new important terms associated with resilience.

Methods: Based on a systematic search of the palliative care literature in medical and social electronic databases in combination with using a continuous process of discourse analysis, in-depth interviews with three experts were conducted. The extracted concepts are discussed in five focus groups with experts. Transcripts are analysed using the software MAXQDA2020.

Results: Major topics emerging from the interviews are a frequent association of resilience with the concept of resistance. While optimism is more associated with something positive, hope seems to be connoted with change. Going along with an already identified strand of discourse about the acceptance of dying, there is evidence of the danger of a normative character of resilience. Especially from the field of mindfulness, new terms like observing and "not-knowing" could be identified.

Conclusion: The results are helpful for the necessary operationalisation of the concept of resilience and provide an important contribution to the critical question, which still needs to be answered, to what extent resilience is a suitable, separate (new) construct in palliative care.

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Abstract number: H-29
Abstract type: Poster

Evaluating mindfulness and compassion training as prevention of compassion fatigue among hospice workers

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Background: Healthcare professionals (HCP) at hospices are at risk for developing compassion fatigue (CF) due to numerous emotional demands and recurrent exposure to death and dying. CF results in reduced capacity for caring for patients and relatives and influences the mental health of HCP. Therefore, interventions that prevent CF are recommended, but research about such interventions' effectiveness remains sparse.

Aim: To evaluate an intervention consisting of mindfulness-based stress reduction (MBSR) and compassion training adjusted to hospice workers.

Methods: The mixed method design consisted of questionnaires on stress, resilience and work ability, delivered to 39 participants pre- and post-attendance. This was supplemented with in-depth interviews, focus group interviews and participant observation. All interviews were conducted as semi-structured, recorded and transcribed. The participant observation was documented with handwritten notes transferred to computer.

Findings: 20 participants were interviewed twice before and half way through the MBSR and compassion training. The in-depth interviews were supplied with 8 focus group interviews including 38 participants and conducted after finalising the training. The interviews integrated observations from the first, middle and last session of training. The qualitative data was analysed thematically and compared to the themes of the questionnaires. Compassion fatigue was related to stressful events either taking place when encountering patients and relatives, interacting with colleagues or due to emotional challenges at home. When establishing a mindful and compassionate attitude these stressful events were approached differently, resulting in feeling more present and less responsible for others' suffering. Quantitative results are presented when analysed.

Conclusion: The study shows potential benefits of integrating MBSR and compassion training at hospice to prevent compassion fatigue and help build resilience.

Abstract number: H-30
Abstract type: Poster

Assessing the Differences of the Religious Commitment of Cancer Patients after Receiving Chemotherapy during One Year

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Background: Cancer patients during their disease process experience complicated moments and situations, in particular receiving chemotherapy treatments. Religion has played an important role as a coping strategy during treatments.

Aim: To assess the differences of the religious commitment of cancer patients after receiving chemotherapy during one year.

Methods: Quantitative, observational, prospective and comparative study. Was performed in a Hospital day unit oncology in Portugal and included patients who were starting chemotherapy. Participants were recruited using random sample technique and was applied a self-filling questionnaire embracing the sociodemographic characteristics, clinical condition and Belief into Action Scale (BIAC). Data collection was performed from February of 2019 to May of 2020, the data was collected before the patients' started chemotherapy (T0) and after a year of receiving chemotherapy (T1). Statistic analysis was performed using SPSS 24. Ethical approval was granted by the Ethical Committee of the hospital.

Results: 332 participants were included; mostly were women (56.6%), mean age of 60.3 (sd=±11.37), with a religious affiliation (93.7%). The most frequent cancer was breast cancer (27.7%) and cancer stage III (45.5%). The mean score of BIAC T0 was 26.0 (sd=± 12.9) and mean score of BIAC T1 26.3 (sd=±11.9). In this study, women experienced higher values of religious commitment than man (Man-Whitney = 5383.0; $p<0.001$). After one year of chemotherapy patients had higher religious commitment (Wilcoxon test = -2.561; p=0.010).

Conclusion: The results showed that after one year, cancer patients experienced higher values of religious commitment, in particular women also had higher values. Therefore, religious commitment is a coping strategy during cancer treatment and the healthcare professional should have the awareness of the religious / spiritual belief and practices of the patients in order to reach a holist approach in cancer patients.

Abstract number: H-31
Abstract type: Poster

Health Social Workers and Death Anxiety in Time of COVID-19

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Background: COVID-19 had infected millions of humans and caused hundreds of thousands of death across the world. Attitudes and fear of death among health social workers can affect their approach to a dying client, so it is necessary to talk about the issue of death and fear of death.

Aims: The aim of this research was to determine the level of fear and anxiety about death in health social workers in time of COVID – 19. Compare level of fear and anxiety about death with the results of a previous study before COVID – 19.

Methods: The Revised Collet-Lester Fear of Fear Scale (FODS) by Collett and Lester (1969) was used to measure fear in four categories: fear of death, fear of death, death others and the dying of others using a 5-point Likert scale. When interpreting the data, the average value is given on a scale of 1–5, where 1 means no fear and 5 very strong fear. Spearman's correlation coefficient and Mann-Whitney test were used to compare the monitored parameters. Results: 89 respondents participated in the research. It was found that the respondents are most afraid of the dying of their loved ones (average 4.01), followed by the death of their loved ones (average 3.85), own dying (average 3.62) and the least fear of their own death (average 2.69).

Conclusion: The results of the study showed that during time of COVID - 19 death anxiety among health social workers increased. They are also more worried about the dying and death of their loved ones.

Abstract number: H-32
Abstract type: Poster

Legacies Arising from the Dignity Therapy: A Case Study of Person with SM and SLA Diagnosis

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Aim: Dignity Therapy (DT) is a brief psychotherapy for terminally ill patients, comprised of a nine questions framework, that helps patients focus on the most important parts of their life. DT was designed to produce a written Generativity Document (GD) whereby the patients can talk about their lives and the most significant moments or thoughts they wish to preserve. The creation of a legacy document within the context of DT is one way that patients may be expressing or fulfilling their generativity needs.

We described the use of DT with a special case of double diagnosis of Multiple Sclerosis (MS) and Amyotrophic Lateral Sclerosis (ALS), with particular attention on generativity.

Method: DT was administered to patient by a psychotherapist working within a multi-professional team. She attended a DT workshop conducted in hospital and she provided DT as described in the standardized protocol. Supervision was provided throughout the entire process by an expert psychotherapist in DT.

Results: DT lasted about four months, in which about 8 meetings were held. This variation compared to the standard protocol was justified by the cognitive impairment of the patient (consequence of MS). During the therapy sessions these targets were defined: acceptance of double illness, acceptance of the end of life, communication with family, meaning of 'the time that remains'. The patient decided to share the GD with family and multi-professional team. Subsequently, the team requested a meeting for the discussion of the clinical case with particular attention on the legacies araising from the DT.

Conclusion: This case report highlights how the DT could improve the patients' care in rare diseases with double poor prognosis. Patients often report the need to be known as people who have a life history, not merely a disease. Knowing their patient as a person can move clinicians towards deeper inquiry, awareness and connectedness within the context of subsequence clinical encounters.

Abstract number: H-33
Abstract type: Poster

The Wisdom to Survive with Cancer in the Narrative from Participants in the Interactive Support Activity for Cancer Survivors

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Background: Cancer survivors have lived long-term and are seeking support to maintain and improve their quality of life. Therefore, we have started an interactive support activity with cancer survivors and their families, medical professionals, and citizens to provide continuous support for cancer survivors to live with peace of mind and dignity. In the process of the activity, we have aimed to foster the wisdom to survive with cancer, but it is not clear how this wisdom is perceived by the participants.

Aims: To identify the wisdom to survive with cancer perceived by participants in the interactive support activity for cancer survivors.

Methods: We used a qualitative descriptive study and conducted semi-structured interviews with 15 cancer survivors; 4 males and 11 females who were participants in the interactive support activity. Age: 25-83 years. The narrative from the interview was analyzed by content analysis.

Results: We extracted twenty-six core categories as the wisdom to survive with cancer, of which 20 were related to the participants' thoughts and behaviors and 6 were related to the interactive support. The former 20 core categories included: "I can't accept the unreasonable reality and resist it," "I can see that I am not the only one in suffering," "I lose my self-worth because I feel alienated from society," and "I can affirm myself as a cancer survivor". The latter 6 core categories included: "dialogue and connection with other experiences", "comfortable acceptance", and "being able to talk freely about feelings".

Conclusion / Discussion: It was suggested that the wisdom to survive with cancer perceived by participants may have a dynamic and complex structure in which through the interaction with relationships and temporality in the interactive support activity, participants are able to make sense of their various experiences, including painful ones, in their own narratives and give them an outline so that they can think "It's okay with who I am now".

Abstract number: H-34
Abstract type: Poster

Development, Delivery and Evaluation of Spirituality and Palliative Care Mandatory Training Programme

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Background: The care of the dying evaluation (CODE) report 2018 highlighted the need to improve spiritual and psychological care for patients and their families. Areas for development included assessment of spiritual needs and emotional support for those experiencing loss out of hours when specialist teams were not present. There was no in-house training available for staff in this specific topic.
Aim: To design and evaluate a bespoke training package on spiritual and psychological care for all clinical staff at our centre, delivered as part of mandatory training.
Method: A member of the Hospital Specialist Palliative Care team, in collaboration with the Trusts' Chaplaincy lead developed a 50 minute education session on spiritual and psychological care for clinical staff, titled 'Spirituality and Palliative care'.
Learning outcomes include:-

- Exploring spiritualty
- Identifying differences between religious beliefs and spirituality
- Exploring professionals' fears in relation to addressing spiritual care

The session was adopted as part of mandatory training and was launched in June 2019. Evaluation was subsequently undertaken by prospective survey of staff upon completion of the training to assess attitudinal change.
Results: 58 participants underwent training during the first 6 months of roll-out. Evaluation indicated all participants felt learning outcomes were met. Most reported increased awareness in relation to own communication skills, assessing spiritual care needs of patients, and those important to them. Qualitative feedback from patients and those important to them on the care of their spiritual and emotional needs has been positive.
Conclusion: This evaluation indicates that delivery of spirituality and Palliative care training increases professionals understanding of spiritual care needs, and confidence in delivering such care within a palliative care patient cohort.

Abstract number: H-35
Abstract type: Poster

Qualitative Analysis of Nurses' Role in Decision Support for Patients with Relapsed or Refractory Leukemia and Malignant Lymphoma

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Background: Patients with relapsed or refractory leukemia and malignant lymphoma are faced with difficult decisions.
Aims: This study aimed to examine the role of nurses in supporting patients who are making decisions.
Methods: The survey was conducted from March 2012 to March 2014. Semi-structured interviews were conducted with 10 nurses who had experience in caring for patients with leukemia and malignant lymphoma, and qualitative content analysis was conducted.
Results: Forty-eight codes, 15 subcategories, and 8 categories were extracted as the role of nurses. The categories were as follows: [Building trusting relationships and timely and easy-talking interactions], [Supportive interactions], [Providing information and opinions with a supportive attitude], [Representing the patient's thoughts from a neutral standpoint], [Providing specific support for the patient's intentions based on the characteristics of hematological malignancies], [Providing an opportunity for the patient to correctly understand the current situation and think about the future], [Providing daily care practices that respect the patient's wishes], and [Actively changing moods and adjusting patient's lifestyle].
Conclusion/Discussion: The nurses practiced cautious and careful interaction with patients who were faced with decision-making. While taking a supportive and neutral stance, they predicted the course of the disease and worked on the patient's awareness, offered specific support based on the characteristics of t hematological malignancies, and actively worked to fulfill the patient's wishes in a difficult situation. Also, they provided daily care that respected the patient's wishes. From the above, it was considered important for nurses to take a supportive and neutral position, to look at the patient's situation and provide the necessary support to fulfill the patient's intentions, and to build up the patient's daily "pleasure" as a role of supporting patients.

Abstract number: H-37
Abstract type: Poster

Exploring Views and Experiences of the Needs Assessment among Palliative Care Healthcare Professionals: A Qualitative Study

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Background: The comprehensive needs assessment in palliative care is the first step in enabling a meaningful initial encounter that explores where and how the team can address patients concerns, values and preferences for care. Yet the approach to achieve this is ultimately unique to each professional and/or team.
Aims: To explore the experiences and views of palliative care healthcare professionals of the assessment of needs in their firsts encounters with patients in palliative care.
Methods: A qualitative study involving twenty semi-structured individual interviews with palliative care professionals from nine institutions was conducted. A content analysis was performed.
Results: The analysis identified three main themes: 1) Building a bond of trust as the central component to successful outcomes in palliative care; 2) talking about palliative care, ensuring conversation that promote patient understanding of palliative care; and 3) promoting participation in care referring to patient and family engagement and shared decision-making in order to guide a patient-centred care plan.
Conclusion: Our findings suggest that palliative care professionals use the needs assessment to enhance the therapeutic alliance with the patient and their family in their first encounters. Perspectives converge on the importance of building on patient and family awareness of palliative care as well as their crucial role in managing care according to their needs.

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Abstract number: H-38
Abstract type: Poster

Spiritual Suffering in Hospitalised People with Advanced Chronic Obstructive Pulmonary Disease: A Phenomenological Study

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Background: Chronic obstructive pulmonary disease (COPD) is the fourth major cause of death, globally. People with advanced COPD are frequently hospitalised yet rarely receive palliative care. They experience multi-dimensional suffering, with considerable concerns about death and dying. However, spiritual suffering is rarely identified nor addressed during repeated hospitalisations. It is important to understand spiritual suffering during hospitalisation to improve care.

Aim: To study the experience of spiritual suffering during hospitalisation in people with advanced COPD.

Method: A descriptive phenomenological approach, following Giorgi's method was employed. Fifteen participants with advanced COPD were recruited from a tertiary care hospital in India. Unstructured interviews were conducted during hospitalisation. In-depth analysis focused on identifying the constituents related to spiritual suffering during hospitalisation. Using imaginative variation key themes were identified from these constituents.

Findings: Key themes identified were, first, purposeless life: while completing family responsibilities gave a sense of fulfilment, unfinished family duties caused loss of meaning of life; second, ambivalent thoughts: extreme thoughts of 'wishing to die but wanting to live' were experienced alternatively during hospitalisation; third, perspectives about God. Here suffering was interpreted variedly: Hindus interpreted suffering as due to 'karma' (sins related to past life) and Christians interpreted suffering as 'redemption for sin'. Both Hindu and Christian participants utilised positive religious coping strategies, such as prayers and religious rituals during hospitalisation.

Conclusion: Family and God are central to coping with spiritual suffering in people with advanced COPD. Understanding spiritual suffering in its context and culture and utilisation of appropriate positive religious coping are important for palliative care professionals to improve care.

Abstract number: H-39
Abstract type: Poster

Spiritual Care at Home: Impact of a Narrative and Interfaith Spiritual Care Intervention on Palliative Patients' Spiritual Wellbeing

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Background: The importance of addressing the spiritual domain in palliative care has been recognized by many. However, empirical studies investigating the impact of spiritual care interventions designed to mitigate patients' diverse spiritual needs are remarkably scarce.

Aim: The aim of this study is to investigate the impact of a six-session spiritual care intervention designed to improve patients' spiritual wellbeing.

Methods: The intervention consists of three main characteristics derived from existing interventions and models in spiritual care: (1) narrativity and the life story; (2) materiality, ritual and embodiment; and (3) imagination. A mixed-methods design is used to examine the perceived impact of the intervention on patients' spiritual wellbeing and to gain in-depth understanding of the way in which such an intervention impacts spiritual wellbeing. Longitudinal, quantitative survey data among patients at three moments time (T0: baseline; T1: 10-weeks follow-up; T2: 20-weeks follow-up) is combined with qualitative data from interviews with patients (at T1) and reflection notes by patients and spiritual caregivers.

Results: Spiritual caregivers provided the intervention to their patients in home-based, palliative care. This presentation reports on the impact this intervention has had on patients' spiritual wellbeing, based on an analysis of both the quantitative and qualitative data.

Conclusion / Discussion: Knowledge on the way in which spiritual care interventions impact patients' spiritual wellbeing in home-based care are a necessity for spiritual caregivers to improve their practice. Moreover, such insights are needed for other professionals when collaborating with or referring to spiritual caregivers in palliative care. In addition to discussing preliminary findings, methodological implications of conducting such a study in times of the Covid-19 crisis are addressed, as are ways in which scholars can deal with these in future research.

Abstract number: H-40
Abstract type: Poster

Attitudes towards Death and Spirituality in Doctors - A Portrait in Analysis

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Death is a process inherent to human existence. Attitudes towards death (ATD) vary in sociocultural, individual and professional terms. The hospitalization of death showed the central role of the health professional in the process and in the construction of a good death. Their attitudes seem to have an impact on the quality of care provision and on the attitudes developed by patients and their families. The training on death and the presence of a meaning for life have shown a positive impact. With this study we intend to recognize the levels of spirituality and ATD and to determine the relationship between them.

This is an observational and cross-sectional study of doctors in Portugal. The sample data was collected in the form of questionnaire, composed of: demographic data; Pinto CR spirituality scale; scale of ATD. For analysis descriptive statistics, followed by multivariate analyzes of variance were used.

Despite the great majority of doctors in the sample have already experienced death processes (94%), the majority (61.1%) had no training in this area in the last 5 years and feel that their training is not adequate (67,3%). Doctors have an average level of spirituality of 2.7 with a predominance of optimism. These showed to be associated with age, religious practice and education. The predominant ATD was neutral acceptance (71.8%), followed by fear and anxiety. ATD showed an association with age, practice, experiences of death, religious practice and training. Spirituality have a significant effect on ATD, leading to positive attitudes.

The unprecedented nature of this study in the medical population can contribute to the establishment of measures aimed at optimizing the process of humanization of death, leading these professionals to positively face their role in monitoring death and consequently conditioning an improvement in the provision of care and of experiences for the patient and the family.

Abstract number: H-41
Abstract type: Poster

Exploring Acceptability of Dignity Therapy within an Italian Palliative Care Services: An Exploratory Case Study

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Aims: Dignity Therapy (DT) is a brief psychotherapy targeting suffering of patients with palliative care (PC) needs. DT question protocol comprised of a nine questions framework, that helps patients focus on the most important parts of their life. Although psychotherapists already used DT in Italy, the feasibility and acceptability of DT by a PC Italian physicians and nurses have not been examined before.

We described a training on DT by a trained psychotherapist addressed to PC physicians and nurses working in oncological hospital and home PC services. In particular, we analyzed enablers/barriers for the use of the instrument as experienced by the trainees.

Design: Exploratory qualitative case study design using a triangulation of field notes from: 1) external researcher, taken during DT training sessions; 2) professionals involved in DT's administration; 3) supervision sessions of DT's administration. Observations were transcribed as field notes and thematic analysis was performed.

Results: Sixteen participants attended the training (6 physicians, 10 nurses). The most of the participants decided not to try DT, but to use some questions without following the completed protocol. Two PC physicians working in the Hospital Specialized Palliative Care Service administered DT. Then, researchers conducted two interviews, lasting 20 minutes about the enablers/barriers for the use of the instrument. Five themes emerged:

i) time required;
ii) awareness of one's role and psychological skills;
iii) patient's disease awareness;
iv) patient's life history;
v) distinguishing DT from Advance Care Planning (ACP) and 'spiritual testament'.

For each, we evidenced key barriers and enablers.

Conclusion: Using DT by PC professionals in hospital may be promising but still challenging. In particular, the instrument must be distinguished from ACP, but the possibility of collecting data on the patients' life history and wishes can support the physicians for an eventual later ACP.

Abstract number: H-42
Abstract type: Poster

Sexuality in Palliative Care: Practical Up-to-Date Guidelines for Overcoming Multidimensional Barriers in Communication, Support and Patient-education Concerning Sexual Needs of Chronically Ill

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Introduction: Sexuality is a basic need of humans. Hence, losing togetherness with loved ones produces a considerable burden to patients and their partners. Unspoken fears and misconceptions, unpleasant symptoms, and treatment-side effects hinder the possibility of promoting sexual health.

Aim: This work aims to promote the awareness of the sexual needs during chronic illness and gives broad practical implications for health care workers to communicate, support, and educate patients and their partners.

Methods: The literature research was conducted between January 2018 to February 2019. After defining the most frequent physical, psychological, and social issues hindering sexual experiences during chronic diseases within the literature, we searched for ways and strategies to promote sexual awareness in health care staff and patients, to alleviate unpleasant symptoms, and promote an open atmosphere to communicate this sensitive topic in in- and out-patient settings. The multidisciplinary team consisted of two medical doctors and four nurses involved in palliative care or oncology.

Results: We found keypoints for patient-education, symptom control, and specific interventions that showed benefits for the promotion of sexual health in cancer patients (Table). The main principles for sexual care in oncology should be the assessment of sexual issues in routine care, to clarify common patient questions (e.g. Is cancer transmissible?), providing adequate symptom control of unpleasant symptoms (e.g., odor), and, if the issues remain present, the referral to a psychologist or sexual therapist.

	Key findings
Communication/ Education	• Include the dimension 'sexuality' in routine assessments and advanced care planning • Sexuality is not just intercourse • Discuss and resolve misconceptions • Educate about drug-side-effects • Acknowledge sexuality as a basic need
Symptom Control	• Prevent odors (wounds), pain (in general, scars), and nausea • Drugs on-demand before intercourse • Schedule intake of sedating drugs • Reevaluate drugs (e.g., beta-blockers, antidepressants)
Interventions	• Evaluate and provide psychological care promoting the body image • Refer to a sexual therapist • Cover stoma and catheters with bandages • 'Do not disturb' signs for in-hospital patient rooms

Conclusion: This guideline provides a comprehensive overview of practical implications for the promotion of sexual health in advanced cancer patients based on recent literature.

Abstract number: H-44
Abstract type: Poster

End-of-Life Experiences (ELEs) in Palliative Care: A Qualitative Study of Coherence and Differences among Reports from Professionals and Patients

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Background: End-of-life experiences (ELEs) include psychological phenomena that occur near death. Most prevalent are vivid dreams or visions while awake, containing deceased loved ones. ELEs can be profoundly meaningful to both patients and loved ones, and have been suggested to be an intrinsic part of the dying process.

Aim:

1) to investigate whether professionals are aware of and report the presence of ELEs among their patients and, if so, how are they perceived.
2) to explore coherences and differences in the reports from professionals to those received directly from patients in the same context.

Methods: Semi-structured focus-groups interviews were conducted with 18 professionals in palliative home care and hospice inpatient units.

Qualitative content analysis was applied to digitally recorded and transcribed interviews.

The results were compared to those previously obtained in interviews with 25 patients, in the same context and time period.

Results: Most (15/18) participating healthcare professionals had experience of ELEs.

There was a coherence between professionals and patients in that ELEs are a positive experience that often contain deceased loved ones and are perceived as real by the patient.

Many professionals, but none of the patients, presumed a connection to medical circumstances.

Both professionals and patients told that patients wanted to talk about their ELEs, but could be reluctant due to fear of ridicule.

Conclusion: ELEs are often perceived as positive for the patient, resulting in feelings of comfort and sometimes lessened fear of death.

Many professionals sought an explanation to ELEs in medical circumstances. This implies a need for education about ELEs as it constitutes a risk of medicalization, depriving the patient of a positive experience.

Regardless of the cause of ELEs, the predominantly positive effect of ELEs can improve quality of life, thereby fulfilling the goal of palliative care, and warrants further attention.

Abstract number: H-45
Abstract type: Poster

‘Things Are Hidden under the Cloth’: Experiences of Masculinity and Stigma from Men with Advanced Prostate Cancer and Family Caregivers in Ghana - A Serial Qualitative Interview Study

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Background: Advanced prostate cancer and its long-term treatment and side effects adversely affect the quality of life of patients in a resource-limited context where family caregivers provide care at home with minimal professional support. Little is known about how men experience changes to their masculinity and associated stigma, within the context of advanced prostate cancer. This paper explores the participants' perceptions of masculinity and stigma for these men in order to inform (development of) appropriate palliative care interventions.

Method: Serial qualitative interviews with men living with advanced prostate cancer (and their family caregivers) in Ghana. Data were collected at two-time points, 8 weeks apart over 6 months. Inclusion criteria: men with advanced prostate cancer and their main family caregiver (at least 18 years old). Data were inductively analysed using thematic analysis.

Findings: The participants (n=23 men; 23 family caregivers) revealed that advanced prostate cancer is associated with multi-layered stigma regarding: prostate cancer, symptoms, treatment, and stigma by association. Perceived breaches to masculinity were: extreme weight loss, reduced patriarchal dominance in socio-cultural and economic roles, inability to suppress emotion (‘men don't cry’), and loss of erectile function. Men try to conceal what is happening to them by ‘hiding things under the cloth’ and this affects health-seeking practices and quality of life. Family caregivers provide compassionate care due to their belief in the reciprocity of care and filial obligations.

Conclusion: Stigma and masculinity-related issues affect the compassion and social connections that are pivotal in palliative care. The findings demonstrate several unmet needs, concealing of information, and multidimensional facets of stigma and masculinity. The reciprocity and filial piety notion could inform a culturally relevant compassionate care intervention to improve the quality care.

I Posters Paediatric Palliative Care

Abstract number: I-06
Abstract type: Poster

Continuous Deep Sedation until Death in Neonates and Infants in Flanders: A Post-mortem Survey

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Background: The use of analgesics and sedatives to alleviate pain and discomfort is common practice in end-of-life care in neonates and infants. However, to what extent those drugs are used in that context with the specific aim of bringing the infant in a state of continuous deep sedation is currently unknown.

Aims: To examine the prevalence and associated clinical characteristics of continuous deep sedation until death in neonates and infants who died under the age of one.

Methods: We performed a nationwide mortality follow-back survey based on all deaths under the age of one that died over a period of 16 months in Flanders, Belgium. Physicians were asked whether continuous deep sedation preceded death, and clinical characteristics associated with the sedation: type of drugs used, the duration of sedation, whether or not artificial nutrition and hydration were provided, intent to hasten death. Data on continuous deep sedation were linked to demographic and clinical information from death certificates.

Results: Response rate was 83% (229/276). In 39% of all deceased neonates and infants, death was preceded by continuous deep sedation until death. Physicians used a combination of morphine and benzodiazepines in 53%, or morphine alone in 45% of all sedation cases in order to continuously and deeply sedate the infant. In 89% of cases death occurred within one week after sedation was started, and in 92% artificial nutrition and hydration were administered until death. In 49% of continuous deep sedation cases there was no intention by the physician to hasten death, and in 40% the possibility of hastening was taken into account.

Conclusion / discussion: Continuous deep sedation precedes about 2 in 5 neonatal and infant deaths. Guidelines for continuous deep sedation in this age group are nonexistent and it is unclear whether the same recommendations as in the adult population apply and can be considered as good practice.

Abstract number: I-11
Abstract type: Poster

What, if Anything, Is an Inpatient Pediatric Palliative Care Unit? A 4-years-Analysis at the Munich Pediatric Palliative Care Center

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Background: The Munich center for pediatric palliative care (PPC) offers specialized home and inpatient palliative care for children with life-limiting diseases and their families. Detailed data on the characteristics of patients cared for in a dedicated inpatient PPC unit are still scarce.

Aims: This study aims at describing patient and care characteristics and complexity on an inpatient PPC unit in order to learn about the challenges and relevance of inpatient PPC.

Methods: Retrospective single center chart analysis of 487 consecutive cases (203 individual patients, 2016-2020) cared for on the center's 8-bed inpatient unit, including their demographic, clinical and treatment characteristics. Data were analyzed descriptively.

Results: Patients' age at admission ranged from 1 day to 35.5 years (median 4.8 yrs, 19% $<$ 1 yr, 7% $>$ 20 yrs). 60% were referred by the center's home care team. Median duration of stay was 11 days (range 1-186). 78% were discharged home. In 11% of cases the patient died on the unit (27% of individual patients). In 37% of cases, there was no accompanying adult. In 18%, an interpreter was needed due to language barriers. Main ICD-10 groups were nervous system (38%) and congenital abnormalities (34%). Only 7% suffered from an oncological disease. The predominant clinical symptoms were acute pain (54%), gastrointestinal symptoms (45%), neurological symptoms (mainly epilepsy, dystonia, and spasticity; 43%) and dyspnea (33%). In 16% of cases, patients were dependent on mechanical ventilation and in 71% they had some type of feeding tube. Half of the cases received parenteral medication and 48% diagnostic imaging.

Conclusion: First data analyses show that patients on the PPC unit suffer mainly from non-oncological diseases. Almost 1/5 were infants. Care needs and dependence on medical technology were high. Most patients could be discharged home. The care level was equivalent to that of an intermediate care unit.

Abstract number: I-13
Abstract type: Poster

Palliative Care Knowledge among Korean Physicians and Nurses who Care for Pediatric Patients

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Background: Since South Korean government launched a pilot project about pediatric palliative care in 2018, training in the care has become crucial. Although assessing the knowledge of healthcare providers enables to design and implement professional training programs, there is no Korean instrument available to measure their knowledge level.

Aims: This study aimed to translate the Palliative Care Knowledge Test (PCKT) and measure the knowledge of palliative care among physicians and nurses who care for pediatric patients.

Methods: After a committee translation, content validity was evaluated by six clinicians working in pediatrics or palliative care. To measure criterion validity, a Palliative Care Quiz for Nursing (PCQN) was included in the survey, along with the PCKT-KV (PCKT-Korean version). A link to a web survey were delivered to physicians and nurses who work in pediatric departments in 8 tertiary hospitals.

Results: A total of 234 healthcare providers (168 nurses, 66 physicians) participated in the survey. Ranging from 6 months to 35 years, the average number of work experience of participating nurses and physicians were 9.23 ± 7.62 and 10.64 ± 8.92 years. The PCKT-KV showed acceptable scale-wide content validity (0.975), and criterion validity (PCQN correlation; r=.349, $p<.001$). The average score of PCKT-KV was 10.95 ± 2.72 (range 1,19). The question with the highest percentage of correct answers (91.9%) was “Q3” about pain control at night. The question with the lowest correct answer rate (11.0%) was “Q11” about dyspnea. Nurses showed higher palliative care knowledge scores than physicians in knowledge about philosophy (p=.009), psychiatric problems (p=.006), gastrointestinal problems ($p<.001$), and total ($p<0.01$).

Conclusion/ discussion: The PCKT-KV is a useful instrument to measure and compare palliative care knowledge of different professions. Further attempts to include more participants from various fields could prove beneficial for country comparisons.

Abstract number: I-14
Abstract type: Poster

Oncologists’ and Haematologists’ Views of What Facilitates or Hinders Referral of a Child with Advanced Cancer to Palliative Care in India

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Background and aim: In India, there is high incidence, low cure rates and increased cancer-associated deaths among children with cancer. Although a significant proportion need palliative care (PC), few are referred or referred late. Oncologists and haematologists gatekeep the referral process. This study explored their views on facilitators and barriers for PC referral.

Methods: 22 paediatric oncologists and haematologists from 13 Indian cancer centres were recruited and interviewed. Data were analysed using reflexive thematic analysis. Findings were interpreted using social exchange theory and feedback intervention theory.

Results: Four themes were generated.

1) Presuppositions about PC where qualifications, experience and being an oncologist conferred power to refer. Oncologists had mixed views about their ability to address PC needs. PC could symbolise therapeutic failure and abandonment, which hindered referral. Trustworthy PC providers had clinical competence, benevolence, knowledge of oncology and paediatrics.
2) Making a PC referral was associated with stigma, navigating illness-related factors, negative family attitudes and limited resources, which impeded PC referral.
3) There was a cost-benefit of PC referral. Symptom management and psychosocial support benefitted the patients. Teamwork, stress reduction and personal growth benefitted the oncologists. Perceived interference and communication by the PC team incongruous with oncologist’s views hindered referral.
4) Suggested strategies for developing an integrated model of PC include clear collaboration between oncology and PC, early referral, rebranding PC as symptom control and accessible, knowledgeable and proactive PC team.

Conclusion: Presuppositions, task and cost-benefit influence referral behaviour. Continuous feedback between PC and cancer providers could foster integration and improve PC management of children.

Abstract number: I-16
Abstract type: Poster

Advance Care Planning for Children with Life-limiting Conditions: Content and Characteristics of Conversations Based on the IMplementing Pediatric Advance Care Planning Toolkit

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Background: Advance care planning (ACP) is a strategy to explore patient values, goals and preferences for future care and treatment, with attention to the physical, psychological, social and spiritual domains. The IMplementing Pediatric Advance Care Planning Toolkit (IMPACT) aims to support a holistic approach of ACP for children with life-limiting conditions and their families. In literature the content of ACP conversations is understudied, yet insight in the conversations is needed to support ongoing development of strategies to support ACP in pediatrics.

Aim: To identify the content and characteristics of ACP conversations and related documentation based on IMPACT.

Methods: Eighteen clinicians caring for children with life-limiting conditions were trained to conduct ACP conversations based on IMPACT. In total, they conducted 27 ACP conversations with five children, 26 mothers and 15 fathers. A thematic analysis was performed on the transcripts of 25 audio records of ACP conversations and the documentation in the medical file.

Results: ACP conversations based on IMPACT had a family-centred content giving insight in the participants' perspectives on living with illness, quality of life and underlying family values. The conversations provided some insight in the families' aims and wishes regarding their child's and family's future. Goals and preferences for future care and treatment were less specified during the conversations. Communication attitudes of clinicians entailed evasive patterns when it came to sensitive issues, including the child's end-of-life.

Conclusion: A structured approach of pediatric ACP conversations led to a comprehensive insight in family values. Defining goals of care as part of ACP occurred to a limited extent. Clinicians need to take a more decisive role in ACP to achieve a shared understanding of goals of care.

Abstract number: I-17
Abstract type: Poster

Challenges in Preloss Care to Parents Facing their Child's End-of-Life: A Qualitative Study from the Health Care Professionals' Perspective

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Background: Bereavement care is an inherent aspect of paediatric palliative care, mainly focused on parental bereavement after child loss. However, Health Care Professionals (HCPs) feel responsible for supporting parents who are grieving losses in their child's end-of-life. As such preloss care is provided individually and thus highly varying.

Aim: To better understand the nature of preloss care, this study aims to gain insight into the challenges HCPs encounter in providing preloss care for parents during their child's end-of-life.

Methods: Exploratory qualitative research using semi-structured interviews with physicians and nurses working in neonatology and paediatrics in 3 university paediatric hospitals and 1 child home care service. A multi-disciplinary team thematically analysed the data.

Results: Twenty-two HCPs participated in this study. From the HCPs' inner perspective, three dyadic dimensions in preloss care delivery were identified that create tension in HCPs: sustaining hope versus realistic prospects, obtaining emotional closeness versus emotional distance, and exploring emotions versus containing emotions. Throughout preloss care delivery, HCPs weighed which strategies to use based on their perception of parental needs, the situation, and their own competencies. HCPs remained with lingering uncertainties on whether the preloss care they provided constituted optimal care.

Conclusion: As a result of the experienced tension, HCPs are at risk for prolonged distress and possibly even compassion fatigue. In order to maintain a positive emotional balance in HCPs, education should focus on adapting positive coping strategies and provide hands-on training. Furthermore, on an institutional level a safe environment should be fostered and well-being could be enhanced through learning by sharing as a team.

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Abstract number: I-19
Abstract type: Poster

Caregiver Burden: Impact of Pediatric Complex Chronic Conditions and the Role of Family Functionality

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Background: International literature on the burden of caregivers of children/adolescents (C/A) with complex chronic conditions (CCC) is scarce.

Aims: To assess informal caregiver burden according to number of CCCs, socio-demographic and clinical data and family functionality.

Methods: Analytical cross-sectional study with informal caregivers of C/A with CCC supported by a portuguese Pediatric Palliative Care Team. Socio-demographic and clinical data, home health care (HHC), caregiver burden scale (Zarit Burden Interview, validated for Portuguese population by Sequeira) and family functionality (Smilkstein Family APGAR scale, Portuguese version by Agostinho and Rebelo) were collected using a structured questionnaire. We used bivariate analysis to compare caregiver burden according to socio-demographic and clinical data, HHC and APGAR score.

Results: 31 caregivers were included; 61% revealed burden (severe in 26%). 4 (13%) received no HHC. 27% of C/A had 1 CCC, 55% 2 and 18% 3 CCC, with no association with caregiver presence of burden (75% vs. 47% vs. 83% respectively, p=0.227). A statistically significant association was observed between the existence of caregiver burden and daily duration of care >/=16 hours (64% vs. 56%, p=0.027), APGAR score (mean 7 vs. 9, p=0.005) and C/A diagnosis group (genetic 80% vs. neurologic 67% vs. neuromuscular 60% vs. metabolic 0%, p=0.047). Caregivers living farther than 100 km from the reference hospital showed higher burden scores (median 63 vs 47, p=0.020). There was a significant negative and moderate correlation between the APGAR and ZBI scores (rS=-0.543; p=0.002). There was no difference with lack of HHC (75% vs 25%, p=0,641).

Conclusion: Caregiver burden was a frequent concern regardless of number of CCC, being associated with daily duration of care, diagnosis group, distance to hospital and APGAR score. It is crucial to raise awareness within healthcare teams to plan interventions focused on reducing caregiver burden.

Abstract number: I-20
Abstract type: Poster

Home-based Cross-sectoral End-of-Life Care for Children and Adolescents with Cancer: A Qualitative Study of Bereaved Family Members and Involved Professionals

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Background: Many children and adolescents with incurable cancer and their families prefer home as the place of care and death. However, this implies a transition of care from hospital to home and establishing a well-functioning collaboration between the close family and a variety of professionals from primary and secondary health care sectors.

Aims: To explore experiences with cross-sectoral collaboration on home-based end-of-life care for children and adolescents with cancer.

Methods: Qualitative study based on semi-structured interviews and written responses to open-ended questions in a purposive sample of bereaved family members and professionals involved in the children's home-based end-of-life care (from the specialized pediatric palliative team, the hospital's pediatric oncology/hematology department and the primary health care sector). Data were analyzed using qualitative content analysis.

Results: Fourteen bereaved family members (parents and grandparents) and 26 professionals (physicians, nurses, nursing assistants, social workers and psychologists) participated. Five main themes emerged from preliminary analysis, describing their experiences of facilitators, barriers and needs in the collaboration on home-based end-of-life care:

- Empathic communication, prognostic understanding and planning of end-of-life care
- Challenging roles and trusting relationships
- Continuous adaptation based on changing premises
- Practical, emotional and professional strains
- Persistent support needs and the long road ahead

Conclusion/discussion: The findings offer a valuable insight into families' and professionals' perspectives, emphasizing honest communication, alignment of expectations, and ongoing and adaptive support, which should be considered in future planning and delivery of home-based pediatric end-of-life care.

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Abstract number: I-21
Abstract type: Poster

Exploration of Parent Experience of Initiation of ACP in Children's Palliative Care. A Qualitative Study

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Background/aims: Paediatric Advance Care Planning (pACP) is advocated in policy and guidelines. The perspective of parents regarding process and factors influencing initiation has not been studied. The aim of this study was to explore the parent experience of initiation of pACP in United Kingdom (UK) and Republic of Ireland (Ireland).

Methods: A purposive sample of bereaved and non-bereaved parents was recruited through children's charities in the UK and Ireland and facilitated by gatekeepers. In 1:1, semi-structured, audio-visual internet interviews parents shared their experiences of pACP initiation. Interviews were transcribed verbatim and thematically analysed.

Results: 17 individual interviews were recorded, 3 fathers and 14 mothers, 8 Irish and 9 UK. 14 were bereaved. Three themes were identified; Family centred care; Unstandardised process and Ramifications.

Family centred care: The need for the child to be seen as a person and part of a family unit, not a condition or labelled was central. Trust that the professional was doing what was 'best' for the child having 'listened to' and 'understood' the family wishes was vital. Rapport with the professionals was beneficial but long-standing relationships did not equate with timely initiation.

Unstandardised process: Discussions of future wishes and care was often not recognised as the beginning of planning ahead. Professionals approaches were unstandardised with no individual process and variations between specialities. Parents recognised the difficulty of initiation for professionals but saw it as the professional's role.

Ramifications: Language ambiguity resulted in parents misconstruing messages or intent. Delaying and avoiding initiation awaiting deterioration resulted in limited time for parents to reflect, accept or reset their mindset to the future.

Conclusions: This study identified the parental behavioural factors involved in initiation of pACP and their perceptions of health professionals.

Abstract number: I-22
Abstract type: Poster

Paediatric Palliative Care at a Cape Town Intermediate Care Facility - A Descriptive Study

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Background: Palliative care (PC) holds at its core the potential to improve the quality of life of children living with life-limiting (LL) & life-threatening conditions (LTC's) & their families. In the South African context, PC is not a recognised specialty & little is known about the specific care needs of these children & the experiences of caregivers & health care workers during the child's stay at an intermediate/step down facility.

Aim: The study aimed to describe the population & care needs of children admitted to the facility, the experiences of their primary caregivers & the health care workers caring for them.

Methods: This study is descriptive in design and used different methods to describe three populations within the study site: the patients, their primary caregivers & health workers caring for them. The health records of 25 patients were reviewed & matched caregivers partook in a three-part questionnaire. Focus group discussions were conducted with 15 health care workers at a single point during the study & data was analysed using a thematic framework analysis.

Results: 48% of patients were referred to the facility for transitional care, the most prevalent diagnosis was Retroviral Disease on Highly Active Antiretroviral Therapy (36%) followed by Cerebral Palsy (32%) & pain was identified as the most prevalent symptom (44%). Most primary caregivers derived emotional strength & spiritual meaning from the experience of caring for their child. Health care workers flagged access to training, resources, & support as essential components to ensuring quality care.

Discussion/ conclusion: Children living with LL/LTC's and their families have complex holistic care needs that require a considered and comprehensive approach. A national PC policy framework has recently been approved by the National Health Council & it is hoped this new development will pave the way to support & sustain PC services at intermediate levels of care in South Africa.

Abstract number: I-23
Abstract type: Poster

Rapid Paediatric Program – Gabapentinoids for Pain

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Background: The Rapid Program Paediatric series seeks to establish the broad utility and adverse effects (AE) of frequently used drugs in "real life" paediatric palliative care (PPC). It is designed to minimise workload for individual sites through multi-site collaboration and enable Rapid and easy data collection.

The Gabapentinoids (gabapentin and pregabalin) are used to manage neuropathic and nociplastic pain in PPC with the two groups most likely to benefit being children with cancer-related neuropathic pain or pain-associated with severe neurological injury.

Clinical use of gabapentin or pregabalin is only supported by very low-quality evidence in children's pain management. However, a pointer to the potential "real life" action of these medications comes from two 2015 pharmacovigilance studies in adult palliative care.

Aim: To examine the effectiveness of gabapentinoids in relieving pain in PPC.

Methods: This international, multisite, prospective observational consecutive cohort study assessed pain and symptoms at baseline (commencement of gabapentinoid) (T0) then assessment of medication effectiveness and AE at 14 days (T1), 28 days (T2), 6 weeks (T3) and 12 weeks (T4) after baseline. AE were measured using NCI Common Terminology Criteria for AE.

Results: Data for 144 patients (M76:F68) with a median age of 9 yrs (range $<$ 1 to 18 yrs) were completed. The most common life limiting illnesses were neurological conditions (55%) and advanced cancer (23%). The median Performance Score (Lansky or Australian Karnofsky) of 141 children was 55% indicating a moderate to high level of disability amongst this cohort. Ninety-five percent of patients were commenced on gabapentin with analysis of dosing, effectiveness and adverse events experienced pending.

Conclusion: The results of this series will be presented including baseline pain scores, improvement over time and any adverse harms that occurred throughout the study period.

Abstract number: I-24
Abstract type: Poster

Improving Perinatal Palliative Care through e-learning

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Aim: The highest number of paediatric deaths occur in the first month of life; 47% of deaths among children $<$5 years of age globally are in neonates. With more women undergoing prenatal testing, timely interventions are possible earlier & professionals need to be equipped to respond with sensitivity & expertise. Integrating a Perinatal & Neonatal Palliative Care (PC) approach has the potential to improve the overall experience including the quality of life & death for the pregnant mother, her foetus/neonate/infant & family. Thus, we aimed to empower professionals to do this through an online education programme.

Design: In 2015 a Perinatal PC (PPC) course was made freely available on a children's PC e-learning platform. The course serves as a taster, offering an introduction to the field & aims to enhance knowledge & confidence in PPC for all health professionals working with foetuses, neonates, infants & their families. Participants engage in reflective assignments, a range of useful resources are available and they receive a certificate upon completion of assignments.

Results: 649 participants from 64 countries representing 8 regions of the world have accessed the course. 49% are nurses, 25% doctors with the rest being social workers, counsellors & teachers. 23% were from the USA & 19% the UK. Most participants report they found the course useful (80%), the information helpful (84%), that their confidence in PPC had improved (70%) & that they would recommend the course to others (95%). The course is available in English, Portuguese, French, Czech & Mandarin, with other translations underway.

Conclusion: With PPC being a new field, accessing education on PPC is essential in order to improve care provision. Whilst evaluation is ongoing, this introductory course has clearly been helpful to many practitioners globally. Work is ongoing to update the course & there are plans for a more advanced course in order to ensure practitioners are knowledgeable & trained in PPC.

Abstract number: I-25
Abstract type: Poster

Experiences with Advance Care Planning for Children with Life-limiting Conditions: A Qualitative Study of Families and Clinicians Using the IMplementing Pediatric Advance Care Planning Toolkit

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Background: The IMplementing Pediatric Advance Care Planning Toolkit (IMPACT) provides a strategy to involve clinicians and families of children with life-limiting conditions in ACP from a holistic, family-oriented point of view, starting early in disease trajectories. Insight in the experiences of families and clinicians with ACP early in disease trajectories is limited.

Aim: To explore how clinicians, children with life-limiting conditions and their parents experience ACP conversations based on IMPACT.

Methods: A multicenter, qualitative interview study using inductive thematic analysis was conducted. A total of 27 cases of children with life-limiting conditions were included in the study from February 2019 to December 2019. Interviews with 18 clinicians, 24 mothers, 8 fathers and 3 children were conducted.

Results: Clinicians and families of children with life-limiting conditions valued to be involved in ACP conversations based on IMPACT. Although it confronted both parents and clinicians with the impact of caring for a child with a life-limiting condition, sharing the family's narrative resulted in a stronger relationship between families and clinicians. This relation was valued as a good foundation to discuss values and preferences for future care and treatment. However, an added value of the conversation regarding defining goals of future care and treatment was experienced to a limited extent.

Conclusion: ACP conversations based on IMPACT facilitate family-centred conversations, that are valued by families of children with life-limiting conditions and their clinicians. Translating narratives into goals and preferences for future care and treatment is not self-evident and may require ongoing conversations and training on the job of clinicians.

Abstract number: I-26
Abstract type: Poster

From intuition to measurement: a qualitative study on paediatric palliative care team experiences' of using the children's palliative outcome scale version 2.

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Background: Paediatric palliative care (PPC) aims to improve quality of life (QoL) of children facing life-limiting conditions, but QoL measures are rarely used by PPC teams. Effective implementation of outcomes measurement instruments is needed to improve individualized quality PPC. In Belgium, PPC is provided through transmural paediatric liaison teams (PLT). This qualitative study is embedded in a larger field-study, in which PLT were invited to use the children' s palliative outcome scale version 2 (CPOS-2) with children and parents they followed-up.

Aims: To understand how PLT experienced using the CPOS-2.

Methods: A standardised 7-item questionnaire with open-ended questions was filled-in by each PLT member who had interviewed families. Furthermore, a focus group (FG) was conducted by the external researcher in each of the 6 PLT, based on a 4-questions interview guide. Synthesis of the verbatim of the FG was validated by each PLT. Findings were discussed with a second researcher then validated through 4 virtual meetings among 12 PLT members.

Results: A total of 73 questionnaires were returned, filled-in by 28 PLT members (5 paediatricians, 20 nurses, 2 coordinators/social workers and 1 psychologist). Thematic analysis was based on 4 main categories from which 3 referred to predefined categories (impact on care, resources discovered, difficulties faced), whereas one new category emerged (meaning-making process). Beyond the metrics, the CPOS-2 is perceived by PLT as a tool to identify overlooked domains, to introduce difficult conversations, to objectify intuitions or to correct preconceptions, and to deepen the relationships with families.

Conclusion: Our results showed an enthusiastic participation of most of PLT to use the CPOS-2. Nevertheless, as sensitive topics may arise when using outcomes measurement instruments, some precautions must be taken to ensure the emotional security of both families and teams.

Abstract number: I-27
Abstract type: Poster

Referral Opportunities to Palliative Care in Pediatric Oncology

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Background: Although outcomes for children with cancer have improved greatly, there remains significant suffering and unmet needs. Using a holistic approach, Pediatric Palliative Care (PPC) aims to lessen this burden, early referral correlated with improved quality of life. Yet, some barriers persist, including lack of well-defined criteria.

Aims: To evaluate opportunities for PPC referral in a Pediatric Oncology Department.

Methods: A list of referral criteria for PPC (opportunities) was developed after a literature review. Medical records of children who died from progressive disease between 01/15-12/19 were reviewed.

Results: 113 children, 51% male. Age at death ranged from 3m-18y (<1y=3%; 1-5y=31%; 6-10y=28%; 11-14y=23%; 15-18y=14%). Most children had solid tumors (46%; 27% hematologic, 27% CNS). Overall, median time admission-first opportunity was 19d (IQR 0-155) and admission-death 1.4ys (IQR 0.7-3.0). The most common opportunities were progressive disease (automatic) and relapse (recommended). Each child had a median number of 3 opportunities (IQR 2-4) for referral.

Automatic	%	Recommended	%
Diffuse intrinsic pontine glioma	2.9	*De novo* cancer with projected EFS < 40%	11.7
Neuroblastoma stage 4	3.2	*De novo* cancer with complex pain/symptom management issues	1.8
Progressive disease	15.5	Metastatic solid tumor	3.2
HSCT referral	10.2	Relapsed cancer	33.9
Admission to ICU	9.1	Ethical conflicts	0.0
Relapse after HSCT	4.1	Need of complex healthcare management at community level	2.6
Enrolment in phase I/II clinical trials	0.6		
Conflicts in management of seriously ill/cognitively impaired/dying patients	1.2		

Discussion: Despite limitations, our study showed that all children who died from progressive disease had opportunities for referral to PPC, some identified very early in the disease course. Validation and widespread use of referral criteria for PPC in children with cancer are needed to foster integration and meet needs of children and families.

Abstract number: I-28
Abstract type: Poster

End-of-Life Care in Children and Adolescents with Cancer

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Aim: Most of the cancer deaths in children are from progressive disease. End-of-life (EOL) care should address the specific needs of these children and their parents. This study aims to document the treatment efforts during their last hospital stays.

Methods: The hospital's records of patients with relapsed/progressive cancer who need inpatient care and died in hospital or prefer to go home after last hospitalization were retrospectively reviewed for the period of 2015-2020. Their demographic findings, symptoms and supportive treatments given in hospital were analyzed.

Results: Eighty-five children and adolescents were admitted for supportive care in their last days of life and stayedmedian 29 days (2-202 days) in hospital. Most common diagnoses were brain tumor (37%), sarcoma (21%) and neuroblastoma (18%). Most common reasons for admission were neurological problems (32%), infections (18%) and dyspnea (15%). Fifty-four percent of patients received chemotherapy (CT) during their stay and 19% needed palliative radiotherapy for symptom relief. The mean duration of hospital stay was longer for patients received CT (47 days vs 29 days, p=0.02). Antibiotics (85%), pain medications (83%), respiratory support (69%) and surgical interventions for pleural effusion or ascites palliation (58%) were also needed. All patients and parents had nutritional and psychological support and average 7 disciplines per patients other than oncology helped caring children including ICU admission in 10 of them.

Conclusion: Although majority are cured there are many children still being lost to cancer. Their EOL care should aim relieving all symptoms needs. It can be very complex and sometimes support strategy can be aggressive comparing adults. Health providers and professionals need to be aware of special and increasing needs for EOL care of children with cancer.

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Abstract number: I-29
Abstract type: Poster

Can Spice of Life Be Measured? A Multicentric Bilingual Study in Belgium Assessing the Quality of Life of Children with Life-limiting Conditions and theQquality of Life of their Parents

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Background: Paediatric palliative care (PPC) aims to improve quality of life but measurement of this outcome remains challenging. QOL measures validated for PPC are lacking. In Belgium, PPC is provided through transmural paediatric liaison teams (PLT).
Aims: To measure the quality of life (QoL) of children with life-limiting conditions and the QoL of their parents followed-up by PLT.
Methods: A socio-demographic questionnaire, the children palliative outcome scale version 2 (CPOS-2), the Fragebogen für KINDer und Jugendliche zur Erfassung der gesundheitsbezogenen Lebensqualität (KINDL) and the Quality of life in life threatening illness-family caregiver (QOLLTI-F) were used in conjunction by PLT during interviews they conducted among children and parents followed-up. Descriptive statistics were conducted on the sociodemographic data, the CPOS-2 and QOLLTI-F scores. Pearson chi square test and the Fisher exact test were used to investigate significant differences between scores. Results were discussed and interpreted with the representatives of six PLTs and compared with results from other studies having used the KINDL and the QOLLTI-F.
Results: A representative sample of 73 children/adolescents were included in the study. Of those, 50% were female, 40% aged 7-17 years and 25% faced oncological diseases. Especially for items focusing on the emotional dimension, children self-reported their QoL as higher than their parents did. The QoL scores were not significantly associated with the condition's severity or impaired activities of child's daily life. Due to the small sample size, results may not be generalized.
Conclusion: This study provides, for the first time, an overview of the QoL of children and parents followed-up by a PLT in Belgium in 2019. QoL scores do not seem to be associated with the severity of the child's disease. This study is currently being enlarged to French PPC teams in order to increase the sample size of included children.

Abstract number: I-30
Abstract type: Poster

The SWiCH Study: A National Survey of Staff Wellbeing in UK Children's Hospices

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Background: In the UK, the children's hospice sector has become increasingly concerned about levels of work-related stress among its staff, stemming from increasing evidence that staff wellbeing is associated with the quality, cost and safety of patient care. It is therefore important to review and develop systems to enhance staff wellbeing and reduce the risk of occupational burnout.
Aims: The SWiCH study, conducted by the Martin House Research Centre at the University of York, was a national survey of staff wellbeing in UK children's hospices. It aimed to increase understanding about the work-related stressors and rewards experienced by children's hospice care staff, and to identify the staff support systems and organisational practices that offer the most potential to enhance wellbeing at work.
Methods: The study was designed in two phases. The first phase included a systematic review that identified the factors associated with the psychological work-related wellbeing of hospice staff, and the development and validation of a new tool to measure work-related stressors and rewards in children's hospice staff. The second phase was a national survey of UK children's hospice staff using the new tool and other validated measures.
Results: We received 583 responses from staff across 31 hospices (22 hospice organisations). This paper presents findings from the survey including the level of burnout amongst staff, the stressors and rewards experienced by staff, and the staff support systems and organisational practices used by hospices.
Conclusion: The study provides important evidence about wellbeing and burnout in children's hospice staff, and increases knowledge about organisational and staff support features that enhance wellbeing. The children's hospice sector has welcomed the opportunity to be involved in this research, and the development work has already shed light on the distinct stressors and rewards experienced by staff.

Abstract number: I-31
Abstract type: Poster

Modified Delphi Survey to Ascertain Stakeholder Consensus on Priority Outcomes for Inclusion in the Children's Palliative Outcome Scale (C-POS)

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Background: There is currently no validated patient-centred outcome measure for use in children and young people's (children's) palliative care within the UK. Evidence demonstrates that end users must be involved in the development of such measures to ensure content validity and uptake.
Aim: To identify and prioritise outcomes to be included in an outcome measure for children with life-limiting and life-threatening conditions (LLLTC).
Methods: A three-round modified online Delphi survey was conducted following CREDES Delphi guidance. Parents/carers/professionals working with children with LLLTCs participated. Round 1:participants prioritised outcomes from those identified in a preceding qualitative study. Items selected by $>$50% were retained. Round 2:participants ranked remaining items. Round 3:feedback and level of agreement (Kendall's W)

from round 2 were reviewed by participants; items were re-ranked and results analysed similarly to round 2.

Results: 82 participated in round 1 (59 professional;23 parent). 27 items were selected by >50% of respondents and retained. 60 participated in round 2. Ranking agreement was weak (W=0.17). 30 participated in round 3. Ranking agreement was moderate (W=61). Agreement between parents and professional rankings was poor (k=0.13). The highest ranked items were pain, living life to the fullest and breathing difficulties. Professionals ranked physical symptoms such as dystonia and nausea more highly than parents. Parents ranked psychosocial concerns such as the emotional impact of illness as a priority. Practical outcomes such as accessing education, financial support and financial burden of care were not a priority for either group.

Conclusion: Consensus on which items to include in a palliative care outcome measure for children was moderate by the end of the Delphi process. Lack of strong agreement was potentially due to the heterogeneity of LLLTCs. Professionals and parents had different priorities on which items should be included.

Abstract number: I-32
Abstract type: Poster

Complex Chronic Conditions in Children: Hospital Use in the Last Year of Life and Involvement of Pediatric Palliative Care

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Backgroung: Worldwide, paediatric palliative care (PPC) services are under development. Evidence on hospital use during the last year of the life (LYoL) of children with complex chronic conditions (CCC) remains scarce yet is critical to inform service planning.

Aim: To assess hospital use during the LYoL in children according to number of CCCs and referral to a PPC team.

Methods: Retrospective cohort study of children (1-18years) with CCC, who died in a tertiary pediatric hospital in Portugal (2014-2019). We extracted demographic and clinical information from routine data including CCCs (*according to Feudtner criteria 2014, which include cancer, neurologic, cardiac and metabolic diseases among others)*, hospital use in the LYoL, interventions in the last week of life, do-not-resuscitate order (DNR), referral to PPC team and place of death. We used bivariate analysis to compare children according to number of CCCs and referral to PPC.

Results: 74 patients were included, 69% males, 10 years median age. The most common diagnosis was cancer (49%); 37% had 1 CCC, 35% had 2 and 28% had ^{3}3 CCCs. The latter group spent more days in hospital in the LYoL (median 79 days vs. 51 days if 2 CCCs and 43 days if 1 CCC, p=0.048). Patients referred to PPC (12, 16%) had higher frequency of DNR (92 vs. 44%, p=0.003), subcutaneous drugs administration (50 vs. 0%, p< 0.001), absence of transfusions in the last week of life (0 vs. 39%, p= 0.007), fewer admissions to ICU (42 vs. 76%, p=0.034) and lower proportion of death in ICU (8 vs. 52%, p=0.009). There was no difference in hospital days (58 vs 51, p=0.328).

Conclusion: Hospital use in the LYoL was higher for children with ^{3}3 CCCs and referral to PPC was associated with decreased aggressive procedures, ICU admission and death, with no difference in hospital days. Although this is a relatively small retrospective study, our findings suggest the potential for PPC to impact on hospital use and improve care for children with CCCs in the LYoL.

Abstract number: I-33
Abstract type: Poster

Project ECHO™ Pediatric Palliative Care: Impact of Tele-mentoring and Education Series in Nepal

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Background: The vast majority (97%) of children needing palliative care live in low- and middle-income countries (LMICs). In Nepal, more than 43 000 children need palliative care, yet access to pediatric palliative care (PPC) is extremely limited. A lack of education for health care providers (HCPs) has been identified as a significant barrier to ensuring access to PPC in LMICs. Project ECHO (Expansion for Community Healthcare Outcomes) is an online training model which provides teaching and support for providers in resource-limited settings.

Aims: To develop, implement, and assess the impacts of a Project ECHO for PPC in the South Asian context. Our specific objectives were to assess participation levels, program acceptability, changes in self-efficacy and attitudes towards palliative care among HCPs as well as self-reported practice changes after six months.

Methods: Electronic surveys were distributed at baseline, at the end of the program (10 weeks), and after 6 months.

Results: The program consisted of weekly 60-minute ECHO sessions conducted weekly (June-August 2020). There were 41 participants who successfully completed the program. Survey respondents included nurses (49%), physicians (39%), and other health care professionals (12%). The majority (88%) worked at government hospitals, and most (55%) cared for 10 or fewer children per month who required palliative care. Scores for comfort and attitudes about palliative care showed improvements after participation in the program, with stronger improvements noted in providing bereavement care and breaking bad news, particularly for physicians.

Conclusions: Project ECHO suggests a novel educational model which can be used to build capacity among health care providers in resource limited settings.

Abstract number: I-34
Abstract type: Poster

Mapping the Care Pathways of Mothers and Fathers Continuing Pregnancy after a Severe Life-limiting Diagnosis of their Unborn Child

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Background: In Germany, research on experiences, needs, and care journeys of parents who decide to continue pregnancy after the diagnosis of a life-limiting fetal condition is still scarce. There are several recommendations but few structured perinatal palliative care (PPC) programs.

Aims: We aimed to (1) reconstruct care pathways from the perspective of parents, (2) explore their care experiences and needs during the process, and (3) identify requirements for a structured PPC program.

Methods: We conducted semi-structured interviews with a purposively selected sample of 11 mothers and 9 fathers who continued pregnancy after a life-limiting fetal diagnosis. We used the Coding Method of Saldaña (2016) to analyze data and compiled templates to reconstruct care pathways.

Results: Care journeys start with a suspicious finding prompting a referral to prenatal diagnostics. Prenatal diagnostics often entails severe parental emotional distress due to dearth of information, lack of sensitivity, and perceived pressure towards abortion. Bad experiences make parents decline further referrals, generating a care gap. Poor coordination among providers and lack of guidance reinforce disorientation. Most parents reach the decision to continue with pregnancy without professional support and choose a trusted midwife or gynecologist as the main contact person. Parents value sensitive caregivers, who respect their choices and offer personalized care solutions. There are no regular referrals to palliative care. PPC plays a minor role during pregnancy but becomes relevant in case of survival of the child. Parents cherished farewell rituals, especially spending time with the deceased child at home.
Conclusion: Caring for parents continuing pregnancy after a life-limiting fetal diagnosis demands sensitivity, especially in the context of prenatal diagnostics, and improved inter-institutional coordination. Early access to structured PPC programs during the prenatal phase is required.

Abstract number: I-35
Abstract type: Poster

Surviving the Death of a Baby: End of Life and the Enormity of Grief

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Background: One in every 150 babies born in the UK is stillborn or dies in the weeks after birth; the leading cause of death in the neonatal period is prematurity. The ability to sustain life at the edge of viability or extreme illness can mean that while resuscitation and early stabilisation is often possible, complications of prematurity, care and treatment mean that death may be unpreventable.
Aims: To explore parents' experiences and perceptions of support during and following the death of their baby.
Methods: A qualitative study was undertaken using Interpretative Phenomenological Analysis (IPA). Ethical approval was obtained from National Health Service (NHS) Research Ethics Committee. A purposive sampling approach was used; participants were at least six months post-bereavement. Seven participants were recruited, including mothers and fathers. Data were collected using unstructured interviews. Data were analysed using IPA.
Results: Four main themes were generated which narrate the participants' experiences and ongoing grief journeys. Themes are presented in the table.
Discussion: Study limitations were acknowledged. The key messages arising from this study were in four interconnected areas. 1. The significance of hearing both 'fathers' and mothers' voices' was considered. 2. 'Consistency in the final days' was focused on: DNACPR conversations in a planned manner and consistency of care and communication. 3. 'Reframing the NICU experience' focused on changing the expectations of healthcare professionals for bereaved parents to return to the NICU for legal documentation and follow-up appointments. 4. 'Parental support' suggestions focused on what was or would have been helpful in their ongoing grief journeys.

	Super-ordinate Themes	Sub-ordinate Themes
1	The enormity of grief	Uncertainty; Realisation; Living through the event; Life without their baby; Hopes and desires
2	Being isolated	Alone and isolated; Isolated from social groups
3	Trying to survive	Wanting their baby to be known; Talking with purpose; Family, friend, peer & professional support
4	Routes to an improved future	Communicating clearly & with care; Reframing the NICU; Mapping appropriate support

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Abstract number: I-36
Abstract type: Poster

Mapping Pediatric Palliative Care Needs in Bulgaria: A Mixed Methods Study

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To date, pediatric palliative care (PC) is uncharted territory in Bulgaria. Our goal was to conduct an investigation among parents, patients (children) and clinicans, as well as the general public to determine the attitudes towards pediatric PC and the scope of unmet needs. Between November 2018 and September 2019 we conducted 1/ a quantitative online survey of the general public with 801 respondents and 2/ 28 in-depth interviews of parents and children, who live and struggle with life-shortening or terminal illness and physicians who treat it. Due to lack of official data, we extrapolated that between 5000 and 8000 children in Bulgaria would require PC services. We found that 85% of respondents had never heard the term "hospice" before and did not know its meaning, but after obtaining a definition, 75% of all respondents deem it an indispensable part of modern healthcare. Most of them think such services should be financed by the state, rather than health insurance or private donations. In interviews even among physicians we encountered a very wide array of ideas what pediatric PC is and what it should look like in a clinical or non-clinical setting, which subset of patients it should address and when it should be introduced into the course of treatment. Parents state that they feel utterly abandoned in caring for their ill child and feel a deep sense of social isolation and helplessness. Most of them share that they do not even consult medical specialists for their child's medical needs, because they feel they know their child better than any physician could. None receive any social or psychological support, neither state-sponsored, nor privately funded. In conclusion, we found that in order to introduce pediatric PC, we have to lay the groundwork first: we need to make a thourough assessment of the legal and administrative framework that is inconsistent or lacking and initiate a wide public discussion about the role of PC for quality of life.

Abstract number: I-37
Abstract type: Poster

Evaluation of Working Conditions of Paediatric Palliative Care Professionals: A French Nationwide Study

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Up to 17% of palliative care professionals suffer from burnout. Nurses often display high levels of emotional exhaustion, while physicians exhibit low levels of personal accomplishment. Fostering open communication and active listening can help prevent burnout and job loss among distressed teams. Paediatric palliative care (PPC) can be an emotionally intensive field of work due to the reoccurring emotional burden of caring for terminally ill children and their families.
Our study aimed to describe working conditions of PPC professionals, work-related burden and its impact on overall employee health.
We conducted a multicentric cross-sectional study of all 21 PPC teams across France from December 2020 to January 2021 using the EVREST 2020 questionnaire (Evolution and Relations in Occupational Health). The 28-item questionnaire was closed-ended to provide quantitative results. Univariate statistical analysis was performed comparing results to the national database of health care professionals (HCP) NAF86.

Eighty-five PPC professionals (physicians, nurses, psychologists, etc.) participated in the study (response rate 75%). PPC teams have more regular schedules, more diversified work and greater access to continuing education in comparison to other HCP. Despite regularity in work hours, PPC teams feel pressured by a lack of time and means to accomplish their work satisfactorily. The majority of teams encounter conflictual situations with families as well as with colleagues. Regular debriefing sessions are deemed helpful by PPC teams.

Challenges and stress in difficult clinical situations may affect the team dynamic. The complexity and diversity of cases requires multidisciplinary and up-to-date knowledge for proper management. Creating space for dialogue and encouraging formal education are possible key points for preventing burnout and increasing HCP satisfaction in the workplace.

Abstract number: I-38
Abstract type: Poster

Parents and Clinicians' Reconceptualisation of the Future for Children with High Risk Brain Tumours as Revealed in Consultations and Home Visits

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Background: Throughout the illness trajectory parents and clinicians face a number of decisions that impact the child's future. The future parents once envisaged is threatened. Parents reconceptualise that future in response.

Aims: To explore:

1) how the future is conceptualised during conversations between clinicians and parents;
2) how parents' and clinicians' concept of the future changes over the course of the illness trajectory.

Methods: 20-month ethnographic study of 19 families including observation and audio-recording of 244 interactions among children with high risk brain tumours, parents and clinicians. We present results from an interactionist analysis of 48 verbatim transcripts (42 consultations; 6 home visits) where the child's future was discussed.

Results: Parents and clinicians began to reconceptualise their views of the child's future at the time of diagnosis and continued to do so throughout the illness. Children's views remained relatively stable from diagnosis and hence are not included here.

Before recurrence of disease, clinicians focused on the close horizon, on getting on with treatment whilst helping families to reconceptualise and manage expectations on the distant horizon. After progression, positions reversed. Parents' vision of their child's future shortened. They focused on pursuing further treatment. Clinicians, however, emphasised the impact treatment would have on the child's future as the child's condition deteriorated and cure was not possible. At the end of life, parents and clinicians focused increasingly on the present and making use of time left.

Conclusion: Parents' and clinicians' conceptualisation of the child's future varied over time, aligning only at end of life. In the interest of optimising communication, clinicians need to maintain awareness of changing views around the child's future. A shared perspective aids in shared decision making and best management of symptoms and well-being throughout the child's life.

Abstract number: I-39
Abstract type: Poster

Reliability and Concurrent Validity of the Children's Palliative Outcome Scale Version 2: A Multicentric Field-study in Belgium

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Background: Promoting Quality of life (QoL) is the main goal of paediatric palliative care (PPC) but assessing it remains a challenge in this particular setting. Instruments to measure QoL in PPC are lacking. A promising outcomes measurement instrument, available in English, called the African Palliative Care Association children's palliative outcome scale (APCA CPOS), with 12 items, has been previously pilot-tested in Belgium for its face/content validity, its feasibility and acceptability resulting in a 22-items CPOS-2.

Aims: To assess the reliability and the concurrent validity of the CPOS-2 in French and Dutch.

Methods: The 6 paediatric liaison teams, during their home/hospital visits conducted interviews with children facing life-limiting conditions and their parents. A sociodemographic questionnaire, the CPOS-2, the Fragebogen für KINDer und Jugendliche zur Erfassung der gesundheitsbezogenen Lebensqualität (KINDL) and the Quality of life in life threatening illness-family caregiver (QOLLTI-F) were used.

Results: Seventy-three families accepted to participate to the interviews. After item analysis, two items were deleted, resulting in a 20-items CPOS-2, which showed a satisfactory internal consistency. However, a standard error of measurement (SEM) of 7.74 % was found, which means that an individual total CPOS-2 score should be interpreted with caution. Furthermore, a good convergent validity of the CPOS-2 with the KINDL, and a divergent validity with the QOLLTI-F scores was found, demonstrating that the same construct - QoL - is assessed by the CPOS-2.

Conclusion: Using factor-analysis and/or item response models on a larger data set will also enlighten the dimensionality of the scale as well as the contribution of items to the measurement of the construct that is targeted by the CPOS-2, namely the QoL.

Abstract number: I-40
Abstract type: Poster

Bereaved Parents' Accounts of Extended Time with their Child: A Multisite Qualitative Study of Parents' Experiences of Using Cooling Facilities Provided by Children's Hospices

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Background: The death of a child is an acutely distressing experience. Evidence on the benefits/value to parents of spending time with their dead child following their death means this is now integrated

into routine practice. UK children's hospices have a tradition of offering parents opportunity to use cooling facilities (CFs: cold bedrooms/blanket/cot) to extend this time by slowing deterioration of the body.
Aims: To explore parents' experiences of the very early days of bereavement, using CFs, and the support they receive from children's hospices.
Methods: Multi-site qualitative study employing in-depth interviews, incorporating narrative and semi-structured components, with bereaved parents whose child had died within the previous 18 months and had used a CF provided by UK children's hospices. Data were analysed using narrative and thematic approaches.
Results: Parents were recruited via 8 children's hospices in England and Wales. A quarter of families approached were recruited, 23 interviews were completed. 9 children had died in the hospice, 8 in hospital, 5 at home, and 1 in a residential facility. 20 used CFs in the hospice and 3 in their homes.
Whilst there was considerable variation in how much time parents spent with their child, all highly valued this because it eased the physical separation, the pain that caused, and meant that final memories of being with their child were positive. There was clear evidence that having multiple opportunities to see their child supported acceptance of the reality of their death: a critical 'task' in the grieving process. Making memories and mementos supported parents in finding new ways to continue their relationship with their dead child.
Conclusion: CFs are a core element of UK children's hospice provision. Findings demonstrate how they support early parental grieving processes. This has implications for informing evidence-based practice within children's hospices and NHS services who are beginning to offer this provision.

Abstract number: I-42
Abstract type: Poster

Consultation of Parents and Healthcare Providers in End-of-Life Decision-making for Neonates and Infants: A Post-mortem Survey

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Background and Aims: End-of-life decisions with implicit or explicit life-shortening intention in neonates and infants are common. We aimed to evaluate how often and in what manner neonatologists consult with parents and other healthcare providers in these cases, and when consultation is dependent on the type of end-of-life decision made.
Methods: We performed a nationwide mortality follow-back survey based on all deaths under the age of one that died over a period of 16 months in Flanders, Belgium. The survey asked about different types of end-of-life decisions, and when an end-of-life decision was denoted if and why parents and/or other healthcare providers had or had not been consulted.
Results: Response rate was 83% (229/276). End-of-life decisions in neonates and infants were consulted both with parents (92%) and other healthcare providers (90%), and agreement was reached between parents and healthcare providers in most cases (96%). When medication with an explicit life-shortening intent was administered parents were always consulted prior to the decision; however when medication without explicit life-shortening intention was administered parents were not consulted in 25% of the cases.
Conclusion / discussion: Shared decision-making between parents and physicians in case of neonatal or infant end-of-life decision-making is the norm in daily practice. All cases without parental consultation concerned non-treatment decisions or comfort medication without explicit life-shortening intention where physicians deemed the medical situation clear and unambiguous, possibly indicating a form of paternalism. Physicians consult other healthcare providers before making an end-of-life decision in most cases, and most often the second opinion is asked of a (fellow) neonatologist.

Abstract number: I-43
Abstract type: Poster

"In the Shadow of the Disease": The Perspective of Parental Caregivers of Children in Palliative Care

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In Portugal, there is an estimate of more than 6000 families who need pediatric palliative care (PPC), but it's the country in Western Europe with the least evolution in providing it. The parental caregivers have been the focus of several studies, due to the impact on their well-being and quality of life. Despite this, most of the literature has been focused on cancer, neglecting other diseases such as neurological, hematological, renal, among others. The present study, of descriptive-exploratory nature, is aimed to contribute to the understanding of the psychological experience of complex chronic disease in parental caregivers. The sample consisted of 14 families of children in PPC, composed by 13 mothers and 1 father, aged between 27 and 48 years, which filled out a socio-demographic and clinical questionnaire and answered a semi-structured online interview based on an incomplete narrative that results from the Unwanted Guest metaphor. The results from thematic analysis evidenced 10 main categories: confrontation with the diagnosis; post-traumatic growth; day-to-day challenges; coping strategies; emotional impact; family impact; future's perspectives; resources and social support; disease's representation; representation of the child with disease. The reduced sample dimension and the influence of Covid-19 pandemic are considered some of the study's limitations. However, this study covered several aspects of the parental caregivers' experience and promoted creative answers through their own perspective. For the psychological intervention, implications are drawn suggesting the identification of resources that promote the activation of key processes in family resilience and reinforce a healthy adaptation. Additionally, the results contribute to the development of specific intervention methodologies for this population in a holistic and eco-systemic approach and suggesting further research exploring father's experience and the hospitalizations' impact.
Funding: by FCT

Abstract number: I-44
Abstract type: Poster

Vulnerable Life, Existential Questions: Towards Better Spiritual Care for Parents Taking Care of a Cchild with a Life-limiting Condition at Home

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Background: Taking care for a seriously ill child and facing child loss can confront parents with existential questions. Parents report a lack of support.
Aim: This study aimed to identify barriers hampering support that meets parental existential needs.
Methods: The focus group study was modeled after a multiple-category design with two rounds. In each round three groups contributed: spiritual and grief counsellors (n=6), healthcare professionals (n=6) and recently bereaved parents (n=5). First, participants shared their own

experiences with regard to barriers to support. In the second round they reflected on barriers identified by the other groups. Data were thematically analyzed by a multidisciplinary research team.

Results: Five key problems were revealed. First, all groups struggled to define existential needs. Second, parents and professionals lacked a clear picture of available support. Spiritual counselling was mistaken for being religious in nature, and grief counselling was associated with care after the bereavement. Third, healthcare professionals mainly related existential needs to end of life discussions. Their curative focus, it seemed, hampers sensitivity for earlier existential needs. Fourth, participants shared that support for existential needs is not structurally embedded in primary care. Finally, care provision stops shortly after the decease whereas parents told questions arose later.

Conclusion: Parents of seriously ill children have existential needs. An approach is required to help healthcare professionals recognize and address existential questions and refer parents to spiritual and grief counsellors if necessary. Insight is needed into the specific support that counsellors can offer. Common language could help to match parental needs and care provision. The question arises: what *precisely* do we mean when we talk of existential needs in pediatric palliative care? If we are to improve support, clarifying this with parents is key.

Abstract number: I-45
Abstract type: Poster

Evaluation of Stakeholder-specific and Systemic Impacts of the Viennese Mobile Paediatric Hospice and Palliative Team MOMO by Means of a Qualitative-based Impact Analysis

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MOMO offers a wide range of services for comprehensive support of children in need of hospice and/or palliative care and their families. In doing so, MOMO coordinates with several cooperation partners.

The impact analysis aims to illustrate the broad spectrum of impacts generated by MOMO for its key stakeholders as well as the added value emerging for the system of mobile paediatric hospice and palliative care.

An impact model consisting of stakeholder-specific impact value chains constitutes the groundwork for the impact analysis. The model was first developed hypothetically. For verifying it empirically, we opted for a qualitative approach and conducted 17 semi-structured guided interviews with key stakeholders of MOMO: parents, MOMO team members and representatives of its cooperation partners. The qualitative approach allowed in-depth coverage of the individual situation of each family. For the data analysis, we resorted to a pragmatic socioscientific approach focusing on identifying impact dimensions.

The impact analysis showed that MOMO is perceived as a one-stop-solution offering individual and tailored care to families. It bundles a multidisciplinary service portfolio targeting the specific needs related to hospice and palliative care, social work, childcare or psychological support of each family. This holistic approach ensures a high efficacy. The main beneficiaries are the attended children and their families as MOMO facilitates homecare even in challenging situations. Cooperation partners also benefit from MOMO's in-depth insight into the familial situation, which facilitates decision-making and saves time.

Thus, MOMO is a central point of contact in the system of mobile paediatric hospice and palliative care, contributing to improved cooperation within the system as well as to its further development. Due to its high impact, MOMO can serve as a best-practice which could be replicated in other settings that are still missing similar support services.

Abstract number: I-46
Abstract type: Poster

Modelling an Appropriate Pain Self-management Intervention for Adolescents with HIV/AIDS in Malawi

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Introduction: Malawi has one of the highest HIV prevalence rates (9.2%), and data suggests 27% pain prevalence among adolescents. Self-management interventions reduce burden of pain and symptoms in adults with HIV, but have not been developed for adolescents. This study aimed to develop a pain self-management intervention for adolescents with HIV and chronic pain in Malawi.

Methods: Cross-sectional in-depth qualitative interviews were conducted with adolescents, caregivers and staff working in HIV clinics.

Semi-structured topic guides were developed and iteratively refined. Data were transcribed verbatim and imported into NVivo software version 12 for framework analysis.

Results: We recruited 21 adolescents,19 caregivers, and 22 staff. We identified the following themes:

Experiencing pain: adolescents experienced both physical and psychosocial pain which resulted into poor drug adherence, hunger, poor sleep, and school absenteeism.

Mitigating pain: Use of traditional herbs and over the counter drugs, and non-pharmacological interventions such as exercises and massage.

Understanding of self-management: The majority of adolescents and caregivers did not understand the concept of self-management, with some explaining it as taking care of themselves or taking medication when in pain.

Preferred mode of delivery for self-management: Some adolescents/caregivers prefer information leaflets, seminars and group sessions facilitated by their peers or staff. However some adolescents/caregivers reported that they prefer face-to-face sessions delivered by staff. This was endorsed by staff professionals who would prefer to facilitate group-based self-management sessions.The intended outcomes of interest were reduced prevalence and burden of pain, pain interference with activities, improved drug adherence and spiritual wellbeing.

Conclusion: Person-centred approach to self-management of chronic pain among adolescents with HIV is needed in order to mitigate the impact of pain.

Abstract number: I-47
Abstract type: Poster

Case Report: Success Factors of End-of-Life Care with Hospital-at-Home in an Infant with Vocal Cord Paresis and Neuropathic Pain due to Leukoencephalopathy with Brainstem and Spinal Cord Involvement

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Background: No cure exists for this rare disease caused by gene mutations. We present an infant with increasing hypotonia, tracheostomy and severe neuropathic pain, receiving end-of-life care (EoLC) for seven weeks with hospital-at-home (HAH) during the Covid-19 pandemic.

Aims: To share our experience about factors contributing to quality of life in EoLC with pediatric HAH

Methods: Prerequisites for hospital discharge:

- Agreement between hospital staff and parents about:
- the need for EoLC

- goals of care and advance care planning, including do-not-resuscitate order
- HAH availability 24/7
- Parents, family caretakers and primary health care workers able to:
    - change the tracheostomy in case of life-threatening dyspnea
    - administer subcutaneous and intranasal medications in case of emergency (ICE)

Results: HAH staff daily tasks:

- monitoring vital parameters and performing systematic symptom scores
- monitoring effects of multimodal symptom- and pain management
- monitoring continuous ambulatory drug devices with morphine and midazolam
- preparation of syringes with fentanyl for intranasal use ICE
- preparation of syringes with high-dose ketamine for enteral use
- coordination of all health-care needs of the family, including psychosocial support

Benefits to the patient and family:

- Improved quality of life
- Less restrictions due to Covid-19; enabling family to receive support from friends
- The child was allowed to die peacefully at home in the care of his parents at 10 months of age

Conclusion: Success factors for EoLC with HAH:

- Detailed and repeated advance-care planning together with the parents
- Adjustment of goals of care during EoLC
- Holistic approach to treatment and care
- HAH staff in position to coordinate all health-care needs of the patient and family including emergencies 24/7

Abstract number: I-48
Abstract type: Poster

Network Knowhow

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This evaluation aimed to gather the views of participants around the added value of the Paediatric Palliative Care Network hosted by project ECHO (Hospice UK.) ECHO - Extension of Community Healthcare Outcomes has the goal of improving decision making by collaborate problem solving feeding into the overarching aim of better and more timely care for patients by influencing decision making and service delivery through a gathering of community of practice together for leaning and support.

Paediatric palliative care is a small speciality and in Northern Ireland numbers are low which results in care being delivered in diverse settings by a range of practitioners with varying levels of knowledge, confidence and competence. The evaluation aimed to review the 2 years of ECHO delivered by using a questionnaire approach to gather participant views through an online survey tool. Participants were required to be registered with the project in order to receive the survey. Analysis of the data returned demonstrated an appetite for leaning in this subject area, with particular focus on the benefits of the case study elements of the curriculum. in addition participants reported an increased confidence in their knowledge base with a high percentage reporting that they had applied something that they had learned from the network community in their practice. Conclusions were that the ECHO - Paediatric Palliative Care Network is a valuable and supportive method to build confidence and competence in a small and diverse group of professionals through sharing of a knowledge base and sharing learning from specific practice examples. Lesson learned included the importance of the participants setting the agenda for learning and the relevance of including speakers from a wider UK reach to help quality assure practice. Attention to this learning has been included in the third year of the programme currently being delivered.

Abstract number: I-49
Abstract type: Poster

Medication Errors Experienced by Children and Young People (CYP) Receiving End of Life Care in the Community: An Evaluation and Call for Action

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Background: The complex end of life care of children and young people (CYP) in the community, involving multi-agency collaboration in a devolved practice framework, introduces risks to patient safety including medication errors. The National Patient Safety Agency (NPSA) in the UK, defines a medication error as "a patient safety incident involving medicines in which there has been an error in the process of prescribing, dispensing, preparing, administering, monitoring or providing medicine advice, regardless of whether harm occurred."
Aim: To examine the occurrence and source of medication errors occurring in CYP receiving end of life care in the community.
Methods: Retrospective review of case records, clinical incidents and complaints received for patients followed by a paediatric tertiary hospital receiving end of life care during the calendar year 2020.
Results: Initial analysis of first quarter data revealed 35 medication errors. 89% of these occurred in the community. No error led to significant harm.
Conclusion: Analysis to date suggests gaps in multi-agency collaboration, training and workforce capacity when delivering end of life care in the community, contributes to medication errors. We propose a "Flying Squad"-specialist palliative care team delivered, clinically governed care package for these patients including prescribing and medications management for safe, coordinated rapid discharge for end of life care.

Table 1. Description of medication errors in the community.

Type of drug error	Percentage of errors	Example of error
Professional administration error	29	Administration of high risk medication without appropriate training
Parental administration error	14	Parent gave 10 times prescribed dose haloperidol
Prescribing error	11	Wrong formulation of omeprazole prescribed
Labelling error	9	Midazolam labelled 8mg instead of 800 micrograms
Mechanical Failure	3	Octreotide overdose due to equipment malfunction
Other	11	Wrong drug left in house for parental use

Abstract number: I-50
Abstract type: Poster

Developing Quality Indicators for Potentially (in)Appropriate End-of-Life Care in Children with Cancer, Neurological Conditions or Genetic and Congenital Conditions: A RAND/UCLA Appropriateness Study

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Background: Monitoring tools for the appropriateness of end-of-life care in children are lacking. No validated population-level quality indicators exist for children with life-limiting conditions.
Aims: To develop and face-validate population-level indicators of potentially appropriate and inappropriate end-of-life care for children with cancer, neurological conditions and genetic/congenital conditions, measurable with administrative data.
Methods: Modified RAND/UCLA appropriateness method. We first identified potential indicators through systematic literature review, scoping review, and expert interviews. Then, 35 unique experts scored potential indicator sets for suitability as indicator via an electronic survey. Indicators without consensus were discussed in 3 group discussions to which 32 experts (26 of 35) participated in November-December 2020. Experts included pediatricians, nurses, psychologists, physiotherapists, pharmacologists, care coordinators, family physicians, social workers from various settings.
Results: Systematic literature review yielded 6 potential indicators for cancer, 1 for neurological conditions, and 4 for genetic/congenital conditions with evidence about an impact on quality of life. After the scoping review and expert interviews, we expanded this to a list of respectively 36, 32, and 33 eligible potential indicators. In the expert scoring round respectively 14, 18 and 17 indicators were immediately selected and 17, 11, 16 were discussed. The final sets consist of 21 indicators for children with cancer, 24 for neurological conditions and 23 for genetic/congenital conditions.
Discussion: We developed and face-validated 3 sets of quality indicators, applicable to population databases that provide opportunities to generate more evidence about appropriateness of end-of-life care in children. The differences between our indicators and those developed for adult populations stress the specificity of end-of-life care in children.
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J Posters Public Health and Epidemiology

Abstract number: J-02
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The Transition from Paediatric to Adult Healthcare is Associated with Increases in Unplanned Hospital Visits for Young People with Life Limiting Conditions

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Background: There are concerns that children with life limiting conditions transitioning to adult healthcare can experience a lack of planning and continuity and, in the UK, coordination post-transfer is often by a general practitioner, who may have limited knowledge of the child and the condition. This may lead to increased unplanned hospital care, due to worse condition management and/or care seeking in a familiar hospital environment.
Aims: To assess any association between being in adult compared to paediatric care and numbers of unplanned hospital visits - Accident and Emergency (A&E) department visits and Emergency Inpatient admissions.
Methods: Secondary data analysis. Healthcare records were requested persons in England aged 12-23 years from 2000-2018. Life limiting conditions were identified from recorded diagnoses. Transition was set as the last inpatient or outpatient record with a paediatric treatment or main consultant specialty (specialties were pre-classified as paediatric, adult or unknown). A&E visits and emergency inpatient admissions were counted for each person in each year. Multilevel negative binomial regression models were used to determine associations between (model 1) A&E visits in a year and transition status (i.e. in paediatric or adult care) and (model 2) emergency inpatient admissions in a year and transition status. Age in year, year of birth, age at transition and sex were also included.
Results: Being in adult care was associated with a 16% (95%CI 1-35%) increase in A&E visits and a 38% (95%CI 15-67%) increase in emergency inpatient admissions compared to being in paediatric care. Year of birth, age at transition and sex were also predictive of unplanned hospital visits.
Conclusion / Discussion: Being in adult care is associated with more unplanned hospital visits than being in paediatric care. Improving transition or extending paediatric services for this population may have the potential to reduce these visits.

Abstract number: J-06
Abstract type: Poster

Understanding Value in End-of-Life Care: A Mix-methods Study of Population-based Data and People in England and Scotland

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Background: Every year more than half a million people die in the UK. Most deaths occur in hospital, which many not always be beneficial. Little is understood about which types of healthcare are most valuable to dying patients and their families and about variation in end of life care provision.
Aims: To understand the care that dying people and their families/carers value, and to examine the extent to which current healthcare systems deliver this.
Methods: We undertook retrospective analyses of large, linked, patient-level datasets in England and Scotland. We also conducted in-depth qualitative interviews with 21 bereaved family members/carers. English primary care data from the Clinical Practice Research Datalink were linked to acute care and mortality data. In Scotland the analysis was population-wide, focused on secondary care. Outcome measures included hospital admissions, critical and emergency care use, primary care contacts and associated costs. These were adjusted by age, gender, cause of death, multi-morbidity, and deprivation status.
Results: Quantitative analyses in both countries revealed steady increases in health care utilization and costs during the last year of life, with sharp increases in acute hospital care in the last month. Care intensity and costs varied by age, cause of death and geographical region. Interacting factors relating to knowledge, expectations and decision making influenced the perceived quality of end of life care.
Conclusions: Our findings lead us to question the extent to which intensive, hospital-based care at the end of life offers value to dying people and their families/carers. The limited resources that we have should be used to deliver the kind of care and support that patients' values. Further

research is needed to improve our understanding of current variations in care. Exemplars of high value care should be identified with a view to informing whole system changes.

Funding: Health Foundation (UK)

Abstract number: J-07
Abstract type: Poster

Knowing that Palliative Care Provision Is Not Limited to People with a Few Weeks to Live Is Associated to More Often Considering All Domains to Be Part of Palliative Care: A Survey among Older People

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Background: Misunderstandings about palliative care can hamper people to realize what care is possible when facing a life-limiting disease.
Aim:

1. (1) Gain insight into whether Dutch older people know palliative care is not limited to people with only a few weeks to live;
2. (2) explore whether this knowledge is related to whether the four domains of palliative care come to mind when thinking about palliative care.

Methods: Data of 1,240 (response 93%) members of the Dutch representative LISS panel aged 65 years and older were used for this cross-sectional study, obtained through an online questionnaire. Participants answered true, false or don't know regarding the following statement: 'Palliative care is limited to people with only a few weeks to live'. Furthermore, they indicated on a list of topics, including the four domains of palliative care, what came to mind when thinking about palliative care. Chi-square tests were performed to analyze the relation between answering the statement correct and demographics and topics.
Results: Of 1,240 participants, 23,5% knew that palliative care is not limited to people with only a few weeks to live. Of the remaining participants, 53.8% answered 'true' and 22.7% did not know. Ethnicity and sex were not related to this knowledge; lower age and higher education were positively related to giving the right answer. The four domains of palliative care all came more often to mind in the group that did know that palliative care is not limited to people with only a few weeks to live than people who did not know this (all $p=<.001$): treating symptoms such as pain and dyspnea (74.2% versus 57.4%), attention to psychological problems (44.0% versus 25.6%), attention to social problems (36.1% versus 17.9%,), and attention to spirituality (41.6% versus 24.3%).
Conclusion: For older people to become aware of possibilities of palliative care, efforts should be done to inform them about what palliative care entails.

Funding: ZonMw

Abstract number: J-08
Abstract type: Poster

Predicting Mortality in Ireland: Development of a Four-year Index and Comparison with International Measures

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Background: Identifying individuals who have a higher mortality risk can assist with healthcare planning, reassessing goals of care, exploring psychosocial and physical issues, and discussing earlier palliative care referral.
Aims: We aimed to develop and validate a four-year mortality index for older adults in Ireland and to compare performance to other established international mortality indices.
Methods: 8,174 older adults aged 50+ in The Irish Longitudinal Study on Ageing (TILDA) in Wave 1 (2009-11) were split into development (n=4,121) and validation (n=4,053) cohorts. Six baseline predictor categories were examined: demographics; cardiovascular-related illness; non-cardiovascular illness; health and lifestyle variables; functional variables; and healthcare utilization. We identified variables independently associated with four-year mortality in the development cohort and attached these variables a weight according to strength of association. We summed the weights to calculate a single index score for each participant and evaluated predicted accuracy in the validation cohort.
Results: The final 10-predictor model assigned risk points for: male 1 point; age (65-69: 2 points; 70-74: 4 points; 75-79: 4 points; 80-84: 5 points; 85+: 7 points); heart attack: 1 point; cancer: 3 points; current smoker: 3 points; difficulty walking 100m: 2 points; difficulty using the toilet: 3 points; difficulty lifting 10lbs: 1 point; self-reported poor physical health: 1 point; and hospital admission in the last year: 1 point. Index discrimination was good (ROC area = 0.78) but not significantly better than equivalent indices developed in US and English data.
Conclusion: This index was predictive of four-year mortality in community-dwelling older Irish adults and may have various uses in research and clinical practice. Equivalence with indices from other very different countries suggests that international generalizability is high.

Abstract number: J-10
Abstract type: Poster

Attitudes toward Medical Assistance in Dying (MAID) and Palliative Care (PC) among the General Public

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Background: Although surveys have assessed the public's interest in PC and MAID, none have assessed interest in both within the same population.
Aims: To investigate the Canadian public's opinions and interest towards PC/MAID and to examine the sociodemographic predictors associated with their interest in PC/MAID.
Methods: A national, cross-sectional online survey was developed and administered via a health research firm to adult members of the public from May to June 2019. Respondents were asked about: whether they had heard of PC; knowledge of elements of the PC WHO definition; and interest in referral to PC/MAID if seriously ill. Univariable logistic analysis was used to determine sociodemographic factors associated with interest in PC/MAID referral. Analyses used data weighted according to Statistics Canada demographic distributions.
Results: Of 1,518 respondents, 1,362 had heard of PC. Of these, 933/1,362 (69%) would be interested in discussing PC referral if seriously ill and 57% MAID; 45% would be interested in both. Those who had heard of PC were more likely to be interested in MAID referral than those who had not heard of PC (782/1,362 [57%] vs 69/156 [44%], $p<0.01$). Among those who had heard of PC, interest in PC referral was associated with older age, being married/common law, being a healthcare professional, having a loved one with a serious illness, and better knowledge of the definition of PC (all $p<0.01$). Interest in MAID referral was

associated with having no religion, non-Conservative political affiliation, and better knowledge of the definition of PC (all $p<0.01$).

Discussion: Members of the public who were aware of PC's definition were more likely to be interested in potential referral to both PC and MAID. Age and experience with PC were associated with interest in PC referral, while religion and political affiliation were associated with interest in MAID. These results will be examined further in multivariable analyses.

Abstract number: J-11
Abstract type: Poster

Exploring Costs, Cost Components and Associated Factors among People with Dementia Approaching the End of Life: A Systematic Review

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Introduction: Understanding the costs of care for people dying with dementia is essential to guide service development, but this information has not been systematically synthesised. We aim to answer: (1) Which cost components have been measured in studies? (2) What are the costs of care and how do these change closer to death? (3) Which factors are associated with the costs of care among people with dementia approaching the end of life?

Methods: CINAHL, Medline, Cochrane, Web of Science, EconLit, Embase and references were searched for any type of study reporting primary data on costs of care for people with dementia near the end of life. All papers were published between 1999-2019. Two authors screened all full-text studies. We calculated the mean costs per person per month for each study and used narrative synthesis and descriptive tables to summarise the results.

Results: 19 studies, 16 from the USA, were identified. The majority of studies included in-hospital, out-of-hospital, community and hospice care expenses paid by insurance companies. Only two studies measured informal costs including out-of-pocket expenses and informal caregiving. The monthly total direct cost of care rose towards death, from $1,787 to $2,999 (USD 2019) in the last 12 months, to $4,570 to $11,921 (USD 2019) in the last month of life. Older age, female gender, black ethnicity, higher educational background, more comorbidities, and dementia severity were associated with higher costs.

Discussion: Cost of dementia care rises closer to death. Informal costs of care represent a substantial component of total costs but have been rarely measured, and there is little information from countries outside the USA.

Abstract number: J-12
Abstract type: Poster

Nationwide Study on the Prevalence and Risk Factors of Acquiring Pressure Ulcers in Palliative Care Units

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Background: In palliative care, patients constitute a particularly fragile population; even more so concerning those who are hospitalized in palliative care units. The prevalence and the incidence of pressure ulcers in patients receiving palliative care, wherever they are being treated, is around 12.4% and 11.7% respectively. Very few data are available on palliative care units.

Aims: To study the prevalence of pressure ulcers in palliative care units in France and to know the risk factors of acquiring a pressure ulcer in these units.

Methods: Nationwide multicentre observational study, on a given day. A questionnaire was completed by a team consisting of a nurse and a physician, based on medical records. The characteristics of the patients hospitalized in the unit were recorded, in particular for those with pressure ulcers. The study was approved by an ethics committee.

Results: Data from 633 patients were collected (56% were women, 40% of patients were aged over 75, 81% were suffering from cancer). 63 (41%) departments out of 152 took part in this study. The prevalence and the incidence of pressure ulcers were 28.8% and 14.1% respectively. 77.4 % of these patients were permanently bedridden, 68% were in a state of clinical undernutrition and 77% were currently receiving psychotropic drugs (these elements are known to be pressure ulcer risk factors). The significant risk factors found in the study for acquiring a pressure ulcer in a palliative care unit are: previous history of pressure ulcers (p=0.0057), the presence of organ failure (p=0.033), in particular heart failure (p=0.012), arterial hypotension (systolic pressure <100) ($p = 0.0339$) and long-term corticotherapy (<0.05).

Conclusion: In these highly medicalised units, we observe a high prevalence of pressure ulcers. Knowing the risk factors of acquiring a pressure ulcer in palliative care units enables preventive measures to be implemented. Following this study, recommendations for good practice will be made.

Abstract number: J-13
Abstract type: Poster

Is Early Palliative Care Associated with Reduced Health Care Cost of End-of-Life Care in Patients with Advanced Cancer?

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Background: It is good practice to perform economic analyses alongside randomised controlled study (RCT). Results of economic analyses make it easier to decide on the next research steps or the possible implementation of the intervention into standard care.

Aim: The objective of this SENS-Economic study is to determine if adding early palliative care structured by SENS to standard oncology care influence health care cost in the last month of life of cancer patients.

Methods: The SENS-Economic study is nested in a multicentre, randomised controlled trial of early palliative care in Swiss oncology patients (SENS). The study intervention consists of a single in-hospital consultation providing early palliative care according to the SENS structure. SENS is a practice-oriented, thematic procedure for assessing, planning treatment and evaluating chronic progressive or potentially life-threatening diseases. SENS takes a participatory approach to strengthen self-efficacy and complements medical-diagnostic and therapeutic procedures.

Results: SENS-Economic analysed data from 43 patients (43% response rate). Absolute overall health care costs in the last month of life that were eligible for mandatory health insurance averaged 558 EUR lower in the intervention arm than in the usual care arm (P=0.64). Results also showed no significant difference in health care utilisation in the last month of life. Descriptive analyses showed that cancer patients in the intervention arm used the hospital emergency room less (-22%) and the emergency phone number of the hospital less (-13%) than patients in the usual care group.

Conclusion: There was no significant difference in health care cost between patients receiving the new intervention and standard care, but the small number of study participants reduces the robustness of this conclusion. Anticipatory planning may effectively reduce emergency room contacts.

Abstract number: J-14
Abstract type: Poster

End of Life and Mortality of the Elderly in France: Are Existing Palliative Care Resources Adequate?

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Context: French demographics are characterized by an aging population and a growing number of deaths. Where do these elderly people die? What are the available palliative care resources? The French Atlas of Palliative Care and End of Life ambitioned to present and analyze data to answer these key public health questions.
Method: We conducted a large scale analysis of national health and mortality data to assess whether palliative care resources are sufficient and adequate for the elderly in France.
Results: In 2018, 609,648 people died in France, 70% were 75 years old or older. 57% of people aged between 75 and 84 years old died in hospital, 22% at home, 11% in nursing homes and 9% in other places. Within this population, the first cause of death is cardiovascular diseases (29%) followed by cancers (22%). In terms of resources, there were, 7500 palliative care beds in 2019 and 428 palliative care mobile teams. All these resources are hospital-based. Although the palliative care offer has increased over the last 10 years, territorial inequalities persist: to date, 26 counties do not have palliative care units, despite these counties having a high rate of elderly.
Discussion: Over the last 20 years, 4 national strategies strove to develop palliative care resources in France. These resources were and remain hospital-based while the proportion of elderly people dying at home and in nursing homes keeps increasing. Palliative care mobile teams lack human resources to care for people outside hospital settings, although this is part of their mission.
Conclusion: This Atlas highlights the need to reconsider the way palliative care resources are allocated across the territory. In light of a growing population, palliative care resources outside hospital settings are becoming increasingly important and necessary.

Abstract number: J-15
Abstract type: Poster

Higher Prevalence of Dementia but No Change in Total Comfort While Dying among Nursing Home Residents with Dementia between 2010 and 2015: Results from Two Retrospective Epidemiological Studies

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Background: Important policy developments in dementia and palliative care in nursing homes between 2010 and 2015 in Flanders, Belgium might have influenced which people die in nursing homes and how they die.
Aims: We aimed to examine differences between 2010 and 2015 in the prevalence and characteristics of residents with dementia in nursing homes in Flanders, Belgium and their palliative care service use and comfort in the last week of life.
Methods: We used two retrospective epidemiological studies in region-wide representative samples of nursing homes in Flanders, namely the Dying Well with Dementia study (2010) and the Palliative Care for Older People in nursing homes in Europe (PACE) study (2015). Samples included residents who died within three months before data collection and had dementia according to general practitioner (GP) and/or nursing home staff. After-death questionnaires were distributed to nursing home staff closely involved in care, GP and nursing home administrator, who all contributed in determining residents' demographic and clinical characteristics. The nursing home staff reported palliative care service use, (e.g. pain assessment), and comfort in the last week of life using the validated Comfort Assessment in Dying-End of Life in Dementia scale.
Results: We included 198 residents in 2010 and 183 in 2015. We found a 15%-point increase in dementia prevalence (p-value < 0.01), with a total of 11%-point decrease in severe to very severe cognitive impairment ($p = 0.04$). Controlling for residents' characteristics, in the last week of life, there was an increase in the use of pain assessment ($+20\%$-point; $p < 0.03$) but no change in total comfort.
Conclusion: The higher prevalence of dementia in nursing homes with no change in residents' total comfort while dying emphasizes an urgent need to better support nursing homes in improving their capacities to provide timely and high-quality palliative care services to more residents dying with dementia.

Abstract number: J-16
Abstract type: Poster

Unmet Need of Palliative Care in People Living with HIV/AIDS

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Background: India is the 3rd largest HIV epidemic in the world. Patients with HIV/AIDS require palliative care for several physical symptoms and require psychosocial support but the burden is not understood well, nor treated adequately as a consequence.
Aims: To assess the burden of various symptoms requiring supportive care in HIV/AIDS in a single tertiary health setting and to determine the unmet need regarding supportive and palliative care in people living with HIV/AIDS (PLWHA) in the region.
Methods: A cross sectional survey of PLWHA presenting to the hospital was conducted using NAT-PD, ESAS-r. Data was collected and analysed using Microsoft excel.
Results: out of 97 patients, 19 had WHO clinical stage 4 disease. 67 patients were on treatment for other comorbidities. 57.7 % of patient were unaware of palliative care. However on explaining the role of palliative care, 92.7 % of patients felt need of supportive care in HIV treatment. Patients had following need (potential or significant) for palliative care: unresolved physical symptoms- 72.2%; problems with activities with daily livings- 37.1%, psychosocial symptoms which is interfering with wellbeing or relationships - 46.4 %; spiritual or existential issues- 43.3 %; financial toxicity- 36%; concern over sexual functioning/ relationship- 29.9; having factors making healthcare more complex- 20.6 %. 66.7 % of caregiver were distressed about physical symptoms of their loved one. 34 % of caregiver had difficulty in providing physical care and 38.2 % had difficulty coping. 44.8 % of caregivers experienced problems that interfered their own wellbeing. Pain (42.3%), fatigue (51.5%), L.O. Apetite (43.3 %), depression (42.3%), anxiety (33 %). In less than 2 % of patients specialists referral was sought.
Conclusion: People living with HIV and AIDS have high unmet palliative care need and require better integration of palliative care among these patients to improve palliative care.

Abstract number: J-17
Abstract type: Poster

Medical End-of-Life Decision Making in Colombian Cancer Patients

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Background: End-of-life (EoL) care of cancer patients often involves complex decision-making processes. Colombia is the only Latin American country with specific euthanasia and palliative care legislation.

Aims: To describe medical EoL decision making practices among cancer patients at the end of life in 3 Colombian hospitals.

Methods: Attending physicians of patients with cancer who died between May 2019 and June 2020 in 3 Colombian hospitals answered a questionnaire on which key EoL decisions preceded death, intentions when deciding not to start or withdraw treatments, and communication about advance directives.

Results: We obtained 261 replies from physicians (response 75%). In 112 (43%) patients, there had been a decision to suspend or not initiate potentially life-prolonging treatment, 16 (14%) of which with an intention to hasten death. For 198 patients (76%) there had been some decision of not initiating treatments. Physicians characterized the intervention in 23% of cases as palliative sedation, and 50% of these sedated patients received hydration. Six patients (2%) explicitly requested to actively hasten their death, for 2 of them their wish was fulfilled. In another 6 patients, medications were used with the explicit intention to hasten death, but without an explicit patient request.

There is a lack of communication regarding EoL: 44% of physicians did not know if their patient had any advance care directives; only 15% had spoken to the patient about the possibility that certain treatment decisions may hasten death, for family members this was 34%.

Conclusion: All types of EoL decisions were being made in our population, including euthanasia and palliative sedation. There is a general lack of communication between physicians and patients regarding advance directives and potential life-shortening effects of treatment decisions. Future research should address specific end-of-life procedures and patients' wishes, as well as availability of palliative care.

Abstract number: J-18
Abstract type: Poster

Health Service Utilisation in People with Life-limiting Illnesses in the Terminal Admission

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Background: As the number of deaths is expected to increase in the developed world, understanding health service utilisation (HSU) at the end of life is essential in planning for health service delivery.

Aim: To describe the HSU at a tertiary hospital in Sydney, Australia of decedents in their terminal admission.

Methodology: We conducted a retrospective review of routinely collected electronic clinical, administrative and death audit data of all patients who died between 2018-2019. Using *t*-test or Mann-Whitney U Tests for continuous data and Pearson's Chi-square test for categorical values, we compared demographic and hospital utilisation data for patients who did and did not have palliative (PC) care access. Regression models are being performed.

Results: Of the 1079 people who were eligible, 731(67.7%) patients were seen by PC. Patients who were seen by PC were more likely to be: older (PC: mean 75.1 years SD 14.1, no PC: mean 71.7 years SD 18.0, $p=0.001$), single/widowed/divorced compared to married ($p<0.001$) [DS1] , born overseas compared to local ($p<0.001$), come from home or other hospital compared to nursing home($p=0.022$)[DS2] , less disadvantaged($p=0.001$)[DS3] , and have cancer compared to non-cancer(χ^2 (1,N=1079)=213.764, $p<0.001$, Odds Ratio 0.06, 95%CI 0.05-0.11). [SC4].

Although no significant difference were found between the PC and non-PC groups in median length of stay (7 vs 6 days), there was difference in the total median cost of the terminal admission ($10,291 vs $16,560), $p<0.001$.

More patients in the PC group had a documented plan prior to death (97.7% vs 62.1%, $p<0.001$).and had their discomfort and stress managed in the last 48 hours of life(88.9% vs 64.7%; $p=0.032$) compared to the no PC group.

Conclusions: In this study, there are differences in demographics, total costs and some indicators of quality of death. Further studies to explain the differences and identify who may or may not benefit from PC may assist with service planning.

Abstract number: J-19
Abstract type: Poster

Increasing Government Sector Engagement in Advance Care Planning Using a Life Journey Approach

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Background: While advance care planning (ACP) policy implementation in the healthcare sector has had a moderate impact, we postulate greater uptake if ACP is introduced earlier in an individual's life journey. Government ministries have relationships and systems that are well positioned to further ACP uptake.

Aim: We aim to develop and implement a comprehensive, multi-sectoral strategy for government ministries to embed ACP activities into the life journey.

Methods: We employed a World Café to facilitate cross-ministry communication and industry-specific consultations with government stakeholders. Feedback on barriers, gaps, and readiness to participate and promote ACP was collected and evaluated. Content analyses of stakeholder feedback and strategic and ministry business plans (2020-2023) resulted in the identification of broad and discrete ACP activities to potentially implement at the government level.

Results: Fifteen opportunities for ACP engagement were identified across various ministries spanning health, justice, seniors, labour, immigration, social services, registries, education, indigenous relations and culture. Activities consistent with the life journey approach include: incorporating ACP into the high school curriculum; mailing ACP resources to individuals turning 65; including ACP messaging at birth, marriage, driver's licence and organ and tissue donation registry processes; incorporating ACP resources in seniors housing facilities; and embedding ACP

into programs serving vulnerable populations (e.g., people with disabilities, Indigenous Peoples, people with mental illnesses, people experiencing homelessness).
Conclusion: Given government's widespread role in society, this inventory of opportunities constitutes the basis for an action plan to promote, disseminate resources and provide early navigation assistance on ACP directly to the public – and thereby capitalize on an individual's life journey.

Abstract number: J-20
Abstract type: Poster

Sociodemographic Characteristics and End of Life Outcomes of Patients who Had Early Palliative Care and those who Either Did Not Have Palliative Care or Had Late Palliative Care Intervention

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Several studies have shown that early referral to palliative care is associated with better end of life outcomes for patients, such as dying at home. 77% of Singaporeans wish to die at home but only 23.6% of the deaths in Singapore from 2017 to 2019 took place at home.
Our study aimed to compare the demographics, clinical characteristics and end of life outcomes of advanced cancer patients who received early palliative care (at least 30 days before death) and those who either did not have or received late palliative care (less than 30 days before death).
Our study included patients diagnosed with Stage 4 cancer, seen in outpatient clinics of a cancer centre and died between 1 November 2015 and 30 October 2017. Demographics, clinical characteristics and EOL outcomes of both groups of patients were compared using the Wilcoxon rank-sum test (continuous variables), chi-squared test (categorical variables) and Fisher's exact test (categorical variables with at least one expected cell count of less than 5).
Of the 2,572 patients included, 23.6% of them had early palliative care. They tended to be younger at diagnosis of Stage 4 cancer, of Subsidized or Non-resident pay class. Patients who received early palliative care had longer time from diagnosis of Stage 4 cancer and time from last chemotherapy or systematic therapy to death. Thoracic cancer patients who received early palliative care had longer time from last radiotherapy to death. Patients who received early palliative care had more lines of chemotherapy or systemic therapy, were more likely to receive palliative radiotherapy and were less likely to die in a hospital.
Our results suggest that a patient's age and payment class is associated with whether they received early palliative care, received late palliative care or did not have palliative care. Early palliative care is associated with better end of life outcomes such as fewer aggressive treatments at the end of life and lower incidences of hospital death.

Abstract number: J-21
Abstract type: Poster

Socioeconomic Burden of a Diagnosis of Cervical Cancer in Women in Rural Uganda: Findings from a Phenomenological Study

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Objective: The aim of the study was to diagnose the socioeconomic burden and impact of a diagnosis of Cervical Cancer (CC) in rural women in the context of low-resourced country Uganda, using a phenomenological inquiry.
Methods: This was a multi-site phenomenological inquiry, conducted at three hospice settings; Mobile Hospice Mbarara in southwestern, Little Hospice Hoima in Western, and Hospice Africa Uganda Kampala in central Uganda. A purposive sample of women with a histologically confirmed diagnosis of CC was recruited. Data was collected using open-ended audio-recorded interviews conducted in native languages of participants. Interviews were transcribed verbatim in English, and Braun and Clarke's (2019) framework of thematic analysis was used.
Results: 13 women with mean age 49.2 and age range 29-71 participated in the study. All participants were of low socioeconomic status. Majority (84.6%) had advanced disease at diagnosis. A fuller reading of transcripts produced four major themes clustered under;

(1) socioeconomic characteristics of women,
(2) Impact of CC on women's relationships,
(3) disrupted and impaired Activities of Daily Living (ADLs), and
(4) Economic disruptions.

Conclusions: A diagnosis of CC introduces significant socioeconomic disruptions in a woman's and her family's life. CC causes disability, impairs the woman and her family's productivity hence exacerbating levels of poverty in the home. High and expensive out-of-pocket expenditure on treatment, investigations, and transport costs further compound the socioeconomic burden. Decentralizing cancer care services to regional centers, making cervical cancer care treatment free , strengthening monitoring mechanisms in public facilities to curb the vice of corruption, increased mass awareness campaigns about cancer, increasing human resource in cancer management, and introducing an introductory course on gynecologic cancers into all health training institutions are recommended.

Abstract number: J-22
Abstract type: Poster

Palliative and End-of-Life Care Data in Ireland (PELCI): Establishing the State of the Nation

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Background: We currently know little about the end-of-life phase in Ireland: where and how people die, what health care they use, and how these data can be used to understand experience.
Aims: This project aims to improve knowledge and understanding of these questions.
Methods: This is a secondary data project. We collate routinely collected data for the period 2013-2018 using official sources: Central Statistics Office (CSO), Hospital In-Patient Enquiry (HIPE), and Specialist Palliative Care Services (SPC) Minimum Data Set (MDS). We first evaluate: cause of death, place of death, healthcare utilization variables, and specialist palliative care variables in acute and community settings. We then assess critically how routinely collected data may be used to understand and evaluate end-of-life experience in Ireland.
Results: Ireland has experienced relatively large improvements in life expectancy in the 21st century, mainly due to reductions in deaths from cardiovascular disease. This trend continues, with a fall from 32% in 2013 in to 29% in 2018. Of all deaths in the state, 40% occurred in hospital, which is lower than the EU average. SPC services are among the most widely available in any EU state but large gaps in access persist, particularly in non-cancer patients. Opportunities to evaluate experience are limited by data availability, but some quasi-experimental methods may be useful.
Conclusion: Future end-of-life policy decisions in Ireland must consider the rapidly ageing Irish population, changes in disease prevalence, SPC availability, and experiences in acute settings. These lessons can inform researchers and policymakers in other high-income countries.

Abstract number: J-23
Abstract type: Poster

Dying in the Era of COVID-19: Experiences of Bereaved Relatives on End-of-Life Care in Different Settings in the Netherlands (the CO-LIVE study) - An Online Questionnaire Study

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Background: The COVID-19 pandemic and restricting measures may have affected end-of life care, including experiences of relatives who lost a loved one.
Aims: To describe experiences of bereaved relatives with end-of-life care for a loved one who died at home, in a hospital, nursing home or hospice during the pandemic, and to examine how restricting measures influenced their evaluation of care.
Methods: Bereaved relatives completed an open observational online questionnaire about their evaluation of end-of-life care as provided to a loved one who died between March and July 2020.
Results: The questionnaire was filled out by 393 bereaved relatives whose loved ones died at home (n=68), in a hospital (n=114), nursing home (n=176) or hospice (n=35). Patients who had died were more often men (49% vs 47%), aged 75 years or older (72%), and had COVID-19 (57%). Patients who died in a hospital more often had COVID-19 (76%) than patients in nursing homes (62%), hospices (43%) or at home (18%). Bereaved relatives were mostly women (81%), aged 45 years or older (82%), and a child (55%) of the patient. Bereaved relatives of patients who died in a hospital most often evaluated medical (79%), nursing (75%) and personal care (72%) as sufficient, whereas medical (55%) and personal care (62%) in nursing homes and nursing care at home (66%) were least often evaluated as sufficient. Hospitals, nursing homes and hospices had implemented visiting restrictions in the majority of cases (76%, 90%, 71%, respectively). These restrictions were negatively associated with bereaved relatives' evaluation of medical and personal care in nursing homes, and medical care in hospitals.
Conclusion: End-of-life care during the COVID-19 pandemic was evaluated most favourably in hospitals and least favourably in nursing homes. Our study suggests that visiting restrictions had a major impact, especially in nursing homes.
Funding: ZonMW.

Abstract number: J-24
Abstract type: Poster

Cultures Affecting Cancer and Palliative Care Clinics: An Inter-sectional Mixed Methods Evidence in Uganda

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Aim: To examine how cultural, spiritual beliefs, and traditions affect attending the clinic for cancer and palliative care, by questionnaires to three tribes in Uganda.
Methods: This was a small mixed-methods pilot survey (n=30) conducted between Sept and Nov 2020 in three regions i.e. central, western, and southwestern Uganda. Purposive was used to enroll participants; cancer patients (five), spiritual and traditional (cultural) leaders (five) from each region. Face-to-face key informant interviews were conducted. Quantitative data was analyzed using descriptive statistics i.e. percentages and frequencies and thematic analysis for qualitative themes.
Results: Traditional, spiritual beliefs and other factors affecting cancer care: Majority; 66.7%, 46.7%, 30.% and 23.3% reported cancer is caused by Infection and catching it from others, witchcraft, heredity (genetics), and punishment from God respectively. Two major themes emerged from the interviews;

(1) Socioeconomic constraints, and
(2) cultural barriers (i.e. traditional, religious beliefs, myths, and practices).

93.3% reported financial limitations as a barrier to cancer care access. spiritual healing, traditional herbal, western medicine, and traditional witchcraft as treatments for cancer were prevalent at 80%, 76.7%, 76.7%, and 23.3% respectively.
Conclusions: Beliefs and traditions are very varied and complex in nature. They significantly impact people's values, norms, cultural practices, religions and spirituality, and also their healthcare seeking behaviors and choices for cancer care, Palliative Care and end-of-life care (EOLC). Study findings underline significant knowledge gap about cancer and its treatment. There's need for; multi-stakeholder approaches to address this gap, including education and awareness creation to demystify myths about cancer, and further research to understand how culture and beliefs impact cancer care. The strategies should be culturally appropriate and sensitive.

Abstract number: J-26
Abstract type: Poster

Health- and Disease-related Data of Inpatients in Palliative Care Units of the Comprehensive Cancer Centers and Other Hospitals in Comparison - Data from the Hospice and Palliative Care Register

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Background: The Hospice and Palliative Register of the German Society for Palliative Medicine and the German Hospice and Palliative Association is a database of core data sets of German palliative care institutions. These data serve for scientific evaluations on supra-regional issues and should inform quality assurance measures in palliative care.
Aim: To explore differences and similarities of health and disease-related characteristics between patients treated in palliative care units in Comprehensive Cancer Centers (CCCs) and other hospitals.
Methods: The data set analyzed included data of patients treated at palliative care units of CCCs and other hospital facilities between 2014 and 2018. In addition to the number of patients treated, the proportion of tumor diagnoses, ECOG status, duration of stay, the proportion of patients who died at the palliative care unit were analyzed. The data were analyzed descriptively using SPSS.
Results: Out of 12,922 patients cared for in palliative care units and recorded in the National Hospice and Palliative Care Register from 2014 to 2018, 61.5% were treated in palliative units in other hospitals. In CCCs the proportion of patients with a tumor diagnosis was 79.8%, compared to 85.1% in other hospitals. The proportion of patients with an ECOG of 4 was higher at admission and discharge in CCCs (admission 45.0%, discharge 55.7%) than in other hospitals (admission 39.5%, discharge 42.5%). The average duration of stay in CCCs was 12.63 days, in other hospitals 11.25 days. The percentage of patients who died in the

palliative care unit is higher in CCCs (CCCs 51.2% / other hospital 45.5%).

Conclusion / discussion: Differences were found mainly in the proportion of patients with a tumor diagnosis, ECOG status and the length of stay. Using these differences there is a tendency for CCCs to have more complex patients than other hospitals.

Abstract number: J-27
Abstract type: Poster

Dissemination, Use and Impact of a Community-based, Conversational Advance Care Planning Intervention: Ripple Effects of the Swedish DöBra Cards

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Background: There is growing interest in community-based advance care planning (ACP) interventions, but few studies investigate the societal impact of such initiatives. A Swedish adaptation of the GoWish cards, the DöBra cards, were used as a tool in the SweACP participatory action research project with older people in the community, without imminent End-of-Life (EoL) care needs. Due to popular demand, the DöBra cards were later made available to the general public as a social innovation.

Aim: To explore how the publicly available DöBra cards have been disseminated and used without researchers' engagement, to provide a basis for understanding their impact in a wider community setting.

Methods: Using a Ripple Effects Mapping approach, we followed three chains of dissemination of the DöBra cards originating in a patient organization, a national interest organization for older people, and in a health care organization. Data were collected through interviews with 20 participants and analyzed with directed content analysis.

Results: A variety of strategies for use were noted, as the DöBra cards were adapted to fit needs in different personal, professional, and organizational settings. The cards were found to act as both a means to raise awareness about EoL issues in different contexts, as well as an end in themselves, e.g. by facilitating ACP conversations for people with serious disease. Resistance, from various instances, to use or promotion of the DöBra cards was however also found. Impact included personal development as well as strengthened personal and professional relationships, with potential to affect EoL care provision.

Conclusions: The broad dissemination of the DöBra cards in a variety of contexts beyond those controlled by researchers, has led to capacity building in dealing with EoL issues in the community, as the topic of dying and death has been brought to agendas in new contexts.

K Posters Policy, including International Developments

Abstract number: K-02
Abstract type: Poster

Palliative Care Teams Reduce Hospital Mortality and Utilization: Causal Evidence from a Quasi-experimental, Nationwide Evaluation in Ireland

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Background: People with serious medical illness have high health care costs and poor outcomes. Palliative care consultation teams (PCCTs) appear associated with lower costs and death at home, but observational studies are at high risk of selection bias and high-quality trials are rare.

Aim: To evaluate the causal effect of PCCTs on in-hospital mortality and health care utilisation for the period 2005-2018 using a quasi-experimental research design.

Methods:

Setting: There are 40 acute public hospitals in Ireland, accounting for 95%< of inpatient admissions and 90%< of hospital deaths.

Population: All adults admitted to a public hospital with a primary diagnosis of advanced cancer, organ (heart, liver, kidney, lung) failure, or Alzheimer's disease.

Research design: Decomposed difference-in-differences (Goodman-Bacon method) to exploit PCCT implementation by different hospitals at different times across the study period. The method calculates a weighted average of all possible two-group/two-period difference-in-difference estimators in the data. We controlled for hospital size and patient catchment.

Sources: We collected PCCT data by hand from each individual hospital. Outcome data and other predictors were routinely collected administrative data.

Results: There were 600,306 eligible admissions in the data, with mortality rate 6% (N=38,595) and mean LOS 10.0 days. Sixteen hospitals (47%) had a PCCT in 2005 and 34 hospitals (100%) had a PCCT in 2018. PCCT implementation was associated with a mean absolute reduction in in-hospital mortality of 0.9% (95% CI: -1.6% to -0.2%), a proportional reduction of 15%; and an absolute reduction in LOS of 0.86 days (95% CI: -1.3 to -0.4), a proportional reduction of 8.6%. Secondary analysis suggests a mean estimated saving per admission of €1200.

Conclusions: PCCT implementation reduced hospital mortality and hospital costs in people with serious medical illness. There is scope to use more widely this method in this field.

Abstract number: K-03
Abstract type: Poster

"Role of Palliative Care during a Pandemic": Contribution for a Pandemic Plan

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Aim or goal of the work: Italy was the first European country to experience COVID-19 emergency. This, in particular, in Lombardy and the northern regions.

In anticipation of a second wave, in October 2020, the Italian Palliative Care Society (SICP) and the Palliative Care Federation (FCP) drew up the document: "ROLE OF PALLIATIVE CARE DURING A PANDEMIC".

Design, methods and approach adopted: Scientific literature was analyzed to study the most effective items in a pandemic plan. The document considers both the specificities of the Italian Health System and the experiences that were carried out in the first months of the emergency. Additionally, in June 2020, FCP surveyed to measure the impact of the pandemic on Non-Profit Organizations. 22 questions about volunteering, fundraising, health workers and care, were submitted to 73 Organizations, 44 of whom managing Hospice or Home Care Units.

Results: Following a model that classifies the activities in four areas, staff-stuff-space-systems, the document ends with some recommendations for the planning of a Pandemic Plan to ensure adequate responses to the palliative care needs in health emergency and, in particular, in the Sars-CoV-2 epidemic.

Conclusion / Lessons Learned: Palliative care specialist teams were involved in counselling for COVID-19 in hospitals. Some Hospices converted for treating COVID patients, and Home Care Units adjusted to face the growing demand from COVID-19 and non-COVID-19 patients. In general, however, patients affected by COVID-19 could not access palliative care, that would have allowed the control of symptoms, the communication with family members, psychological support and the promotion of decision-making processes.

Abstract number: K-04
Abstract type: Poster

An International Policy Review of Routine Statutory Data Collection and Reporting in Palliative Care

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Aim: Deficits in data collection related to palliative care in Ireland hamper efforts to evaluate service quality. We undertook a narrative synthesis of the literature to collate the evidence of best practice in the use of routine statutory data to evaluate palliative care delivery, in countries with well developed services.

Methods: Countries were included in the review if they were members of the OECD, had universal health care, were ranked 4a or 4b in the Global Atlas of Palliative Care, and ranked in the top 20 of the Economist Quality of Death Index.

Data collection combined three methods to identify relevant policy and practice documents: (1) review of governmental, academic, and health organisation websites; (2) review of the grey literature; and (3) Google and Google Scholar searches.

For countries with a palliative care dataset, the following data points were extracted: description of the dataset; how the dataset is populated; how the dataset is used; governance; implementation and sustainability; and noted limitations.

In countries without a national dataset, documents were reviewed in relation to efforts to develop the data infrastructure. A country-level narrative synthesis was created and its accuracy verified with local experts.

Results: There was significant heterogeneity in the data infrastructure of the 16 countries examined. Some have national datasets while others collate multiple sources capitalising on the availability of a unique health identifier, enabling patient level indicators to be measured. There is a notable lack of information on community-based palliative care, primary palliative care, as well as a scarcity of outcome measurements in the datasets.

Conclusion: Activity datasets such as that used in Ireland and elsewhere provide limited information on the quality of palliative care services. This review provides learnings for policymakers and researchers seeking to enhance data collection practices to improve and evaluate services.

Abstract number: K-05
Abstract type: Poster

A European Survey of the Palliative Care of People with Amyotrophic Lateral Sclerosis

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Background: Previous studies have shown that palliative care services are more often involved in the care of people with ALS than other neurological diseases.

Aims: This study asked palliative care specialists across Europe how they collaborated with neurology in providing care for ALS patients and other neurological diseases.

Methods: A voluntary online survey was advertised through palliative care and neurology associations for completion by palliative care specialists.

Results: 298 people started the survey, but only 121 completed, from 11 European countries, with the majority from Switzerland (13%) and Italy (74%). The services involved were in the community (75%) or inpatient settings (79%). Multidisciplinary team working was reported but occupational therapy (27%), speech and language therapy (22%) and spiritual care (41%) were less represented.

94% reported seeing people with ALS. However, this was often late in the disease progression with 40% only becoming involved when patients were at the end of life or the terminal phase. Joint clinics were held with neurology (33%) and there was regular telephone contact (44%).

Palliative care was also involved in the care of people with cerebral tumour (94%) but less often with Parkinson's disease (80%), stroke (83%), multiple sclerosis (64%) and rarely with Huntington's disease (35%) or cortico-basal syndrome (32%). The barriers to collaboration included the reluctance of neurology to refer (42%), financial or resource issues (20%) and patient or family reluctance to see palliative care (17%).

Conclusion: Palliative care services are involved in the care of people with ALS but often only in the later stages of disease progression, despite guidelines recommending earlier involvement. The involvement with other neurological disease is variable but the reluctance of patients and families to see services is uncommon.

Abstract number: K-06
Abstract type: Poster

Mortality within 30 Days of Receiving Immune Checkpoint Inhibitors

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Background: Cancer treatment has expanded significantly since the emergence of immunotherapy. Mortality rate within 30 days of chemotherapy has been accepted as a key performance indicator (KPI) for quality oncological care delivery but there is limited data on whether the same standard should apply to immune checkpoint inhibitors (ICIs).

Aim: To assess the 30-day mortality of patients treated with ICIs over a 1-year period

Methods: A retrospective, single-centre review of electronic and paper medical records of patients treated with palliative intent ICI therapy in a tertiary referral centre (Sept 2019-Aug 2020). Data, including patient demographics, diagnosis, treatment and cause of death, was collected on patients who died within 30 days of last administered treatment.

Results: 82 patients received a total of 482 treatments with ICIs. Of these, 8 (9.8%) patients received treatment within the last 30 days of life. The median age was 60 years (45-78). The cancer types were non-small cell lung cancer (2), melanoma (2), renal cell cancer (2), gastric cancer (1) and mesothelioma (1). 5 patients received nivolumab, 2 pembrolizumab and 1 nivolumab and ipilimumab. ICI therapy was first-line treatment for 3 patients, second-line for 3 patients and third-line or more for 2 patients. The majority (5) died within 30 days of their first cycle of an ICI. 7 of 8 deaths were due to disease progression, cause of death was unknown in 1. 7 died in hospital and 1 at home. 7 were linked with palliative care.

Conclusion: Our study demonstrates a 30-day mortality rate of less than 10%, within the accepted KPI as per national guidelines for chemotherapy. ICIs have a more tolerable side effect profile than chemotherapy and the potential for dramatically improved outcomes. However, response rates vary and this prognostic uncertainty challenges our ability to prepare patients for the future. Treatment with ICIs should be given careful consideration in order to ensure quality of care.

Abstract number: K-07
Abstract type: Poster

Helping Non-specialists Improve Assessment of 'End of Life Care' Phase in Structured Judgement Reviews

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Aims: To assess the effect of supporting clinicians by providing quality indicators enabled better assessment of the 'end of life care' phase of Structure Judgement Review.
Background: The Royal College of Physicians (UK) introduced National Mortality Case Records Review (NMCRR) programme and the Structured Judgement Review (SJR). Assessment of the 'end of life care phase' in SJRs are often undertaken by a clinician without expertise in palliative medicine.
Methods: In 2018/19 review of the results of SJRs showed that 96% of care at the end of life was judged good or excellent which was out of step with the other phases of care and the overall review. Criteria were developed in 2019 to guide non specialists in assessing the quality of the 'end of life' phase. 75% of SJRs carried out in Oxford, UK were reviewed in 2020 - assessing the phase of care score and the text relating to care at the end of life
Results:

Phase of care score	2018/2019	2019/2020
Very poor (1)	0	0
Poor (2)	1	4
Satisfactory (3)	0	4
Good 94)	13	12
Excellent (5)	12	5
% rated good or excellent	25/26 = 96%	17/25 = 68%

Prior to the introduction of the quality indicators 96% of EOLC was judged good or excellent. Afterward 68% of EoLC was judged good or excellent in keeping with other phases of care.
Conclusion: Supporting clinicians by providing quality indicators enabled better assessment of the 'end of life care' phase of SJR. In 2019/20 the distribution of scores is more in line with other domains across the SJR. The scores align with the written information on the SJR forms.
Resources: Quality indicators available to all delegates for their use.

Abstract number: K-08
Abstract type: Poster

Worldwide Estimated Morphine Need for Pain in Advanced Cancer: Proportions Feasibly Met by Country Estimated Requirements and Consumption. Retrospective, Longitudinal Cross-sectional Study (1997-2017)

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Background: Countries submit morphine requirement estimates (which place upper limits on stocks/trades) and report consumption to International Narcotics Control Board (INCB). Morphine consumption is increasing worldwide, but estimated need is unreported, so changing proportions of need met by requirements and consumption are unknown.
Aims: To estimate:
Morphine need of people who died from cancer;
Proportion of need theoretically met by requirements + consumption;
Changes over time
Methods: Retrospective, longitudinal, cross-sectional study estimating need for morphine in this group. We calculated gaps between estimated need and total *theoretically* treatable population with estimated requirements and consumption, using INCB methods (1997, 2002, 2007, 2012, 2017).

Table 1.

Data retrieved (1997, 2002, 2007, 2012, 2017)	Analysis	Results reported
Cancer deaths by country (n=196 all years) Retrieved from: www.ourworldindata.org/cancer INCB country estimates of requirements and consumption. N (each year) = 176, 181, 186, 186, 187 Retrieved from: www.incb.org	**Estimated need** n (each year) = 176, 181, 186, 186, 187 Calculated using INCB assumption that 80% of people who die from cancer will morphine treatment (Total deaths * 0.8)	Total proportion of need met
	Proportion of need theoretically met by requirements n (each year) = 176, 181, 186, 186, 187) Requirements / estimated need *100	% of countries estimating requirements theoretically meeting >≤100% of estimated needs 5% percentile groups of proportion of need met
	Proportion of need theoretically met by consumption n (each year) = 143, 154, 156, 144, 152 Consumption (g) / estimated need *100	% of countries estimating consumption theoretically meeting >≤ 100% of estimated needs 5% percentile groups of proportion of need met

We present a best (but unlikely) case assuming all requirements and consumption was for decedents at INCB-recommended dosage/duration.
Results: Estimated need increased from ≈ 6 to 8 million people from 1997-2017. From 1997 theoretical availability of morphine increased, from estimates sufficient to meet 86% of estimated need, to 701% in 2017. However, proportions of countries estimating requirements theoretically meeting >100% of estimated need rose only from 16-30% (1997-2017). In 1997 only 18 countries (13%) reported morphine consumption levels theoretically meeting >100% of estimated need; increasing to 29 (19%) in 2017. In 4/5 included years, the highest proportion of countries reported consumption sufficient to meet only 1-5% of estimated need if all consumption was for advanced cancer (1997, 24%, 2002, 21%, 2007, 27%, 2012, 26%).
Conclusion: Most countries submitted morphine estimates and consumption with zero feasibility of meeting estimated need of people who died from cancer, 1997-2017. Increases in adequacy of estimated requirements and consumption were minimal in 25 years. Annual publication of country-estimated morphine need using INCB-methods is essential for driving accountability.

Abstract number: K-09
Abstract type: Poster

Priorities and Opportunities for Palliative and End of Life Care in National Health Policies: A Documentary Analysis

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Background: Access to high-quality palliative and end of life care is inadequate for most people with serious illness. Health and social care policies are a fundamental mechanism to improve access to quality care.
Aim: To identify priorities and opportunities for palliative and end of life care within current UK national health policies.
Design: Documentary analysis consisting of 1) summative content analysis to describe the extent that palliative and end of life care is referred to within national health and social care policies, and 2) thematic analysis to explore policy priorities that present opportunities for wider access.
Data sources: Policies were identified through web searches of government organisations and expert consultation. Document inclusion criteria were UK-wide or devolved (England, Scotland, Northern Ireland, Wales) overarching health and social care government policies published from 2010.
Results: 15 policy documents were included in the analysis. 12 referred to palliative or end of life care; details about what should be improved or the mechanisms to achieve this were sparse. Policy priorities that provide opportunities to widen access to palliative and end of life care comprised three inter-related themes:

1) integrated care, conceptualised as reorganisation of services as a way to enable improvement;
2) personalised care, conceptualised as allowing people to shape and manage their own care; and
3) support for unpaid carers, conceptualised as enabling unpaid carers to live a more independent lifestyle, balancing caring with their own needs.

Conclusion: Information on palliative and end of life care in UK policies was sparse. Palliative care may provide a mechanism for achieving policy priorities of integrated care, personalised care, and support for unpaid carers. Aligning evidence for palliative care with the three priorities identified may be an effective mechanism to both strengthen policy and improve care for people with serious illness.

Abstract number: K-10
Abstract type: Poster

Towards Person-centred Care for People with Advanced Cancer and their Families in China: What Core Outcomes Matter?

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Background: Cancer is the leading cause of death in China. People living with advanced cancer have multidimensional concerns requiring person-centred care. Routine use of patient-reported outcome measures (PROMs) improves outcomes. However, little evidence exists on ideal outcome measure reflects the breadth of concerns for advanced cancer patients in China.
Aims: To identify the main symptoms, concerns and the priority outcomes for advanced cancer patients and family members, explore views on introducing PROMs into routine care, and devise a model for person-centred advanced cancer care in China.
Methods: Semi-structured qualitative interviews with advanced cancer patients and family members at an inpatient oncology ward were performed between October and December 2019 in China. Interviews were analysed utilizing framework analysis.
Results: Patients (n=20, median age 55.0, 60% female) and family members (n=20, median age 41.0, 45% female) described distinctive but highly interrelated concerns related to living with advanced cancer across five domains: physical and psychological symptoms (e.g. pain), financial difficulties (e.g. debt), impacts on family (e.g. change of roles), coping and adapting to the disease (e.g. decision making), and plans to the future(e.g. attitudes toward dying and palliative care). A conceptual model showing the perspectives of stakeholders has been developed. Findings confirmed that advanced cancer has far-reaching implications for patients and family members in China, extending beyond physical and psychological problems into social, practical and information needs.
Conclusion: This study advances the understanding of patients' and family members' experience and presents a novel multidimensional conceptual model of person-centred care. Routine use of PROMs could be beneficial to stakeholders. This insight is a critical first step in the delivery of more person-centred care for patients with advanced cancer and family members in China.

Abstract number: K-11
Abstract type: Poster

Hospice Inpatient Falls; Improving Medical Assessment and Documentation

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Background: Hospice patients are particularly vulnerable to falls and injury. There are no clear guidelines on what a post fall medical assessment should entail. Current hospital assessment tools are based on non-hospice patients and therefore don't always run in harmony with the goals for a palliative care approach. We reviewed medical documentation post falls and designed an appropriate post fall proforma.
Aims: To Review doctor's medical assessment and documentation post fall. To design a post fall proforma to ensure consistent medical assessment. To re-audit after a period of 3 months with the proforma in use.
Standards: The NICE guideline Falls in Older People and the NPSA Slips Trips and Falls Policy.
Methods: We carried out an Audit of falls via Q-Pulse over a 4 month period- Nov 19 – Feb 20 -looking specifically at the medical documentation in relation to the fall. Using the NICE Guideline and the NPSA Policy, we identified certain data points that should be recorded by the doctor in the notes post fall. Following the development of a falls proforma, we trialled it in clinical practice and re-audited after 3 months.
Results: Our documentation was poor in the initial audit. The fall date and time and basic observations were documented in less than 30%. GCS was not documented in any. Documentation for visible injury/bleeding was 60%,head injury was 40%. Other systems examined were poorly documented. Risk assessment was documented in 20% of notes but medication review was evident either in the assessment or management plan. On re-audit with the proforma, there was a dramatic improvement in documentation of basic identifiers, observations, GCS and serious injury. Risk assessment was completed $>$80%.
Conclusion: A post fall medical proforma ensures thorough assessment and subsequent management. It thus acts as a useful guideline, where only pragmatic interventions consistent with the hospice philosophy are adopted.

Abstract number: K-12
Abstract type: Poster

Ensuring a Good-death Globally: What's the Problem Represented to Be?

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The endorsement of palliative care by the World Health Organization (WHO) has helped disseminate 'palliative care' as a strategy for end-of-life care to health systems worldwide. Additionally, 'palliative care' has been included as a priority and fundamental requirement of the Universal Health Coverage agenda. Ensuring universal access to palliative care encompasses assessing the implications of transfer of concepts and values from one context to another, with differences of political, cultural, social nature. This poststructural analysis aimed to bring visibility to conceptualisations of 'palliative care' and their associated implications for the universal coverage agenda. The What's the Problem Represented to Be? (WPR) framework was applied to key WHO guidelines to systematically investigate the meaning construction underpinning them and to explore how such meanings constrict the ways in which 'palliative care' can be understood. Data gathering occurred through an interpretive exercise in which to build the territory of analysis followed by the application of the WPR framework. This included multiple strategies including discourse analysis; genealogy; archaeology; identifying silences; and the analysis of the 'lived effects' by reflecting on the implications of particular conceptualisations for individuals and practices. Findings suggest forms of regulation embedded in discourses of 'personhood' and 'good dying' that favour Anglo-Saxon countries; cultural specificities of end-of-life transferred to the individual sphere and the downplayed role of structural inequalities to emphasise the increase of palliative care coverage. This study has implications for the 'universal coverage' agenda as it challenges the universality claim of palliative care guidelines. Research supported by Doctoral Scholarship Award from the University of Strathclyde.

Keywords: Policy analysis; critical policy studies; world health organization

L Posters Development and Organization of Services

Abstract number: L-02
Abstract type: Poster

Economic Evaluation of the Palliative Care Home Support Packages (PEACH) Program

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Background: Economic evidence in palliative care is important for making decisions regarding allocation of resources and support patient preferences for end-of-life (EOL) care. However, there is limited evidence on the cost-effectiveness of palliative and EOL care to inform healthcare funding decisions.
Aims: To evaluate the cost-effectiveness of providing Palliative Care Extended Packages at Home (PEACH) in addition to usual care to support clients in their wish to be cared for, and die at home.
Methods: A modelled cost-effectiveness analysis was conducted from a healthcare provider perspective to estimate the incremental costs, effects and cost effectiveness. De-identified prospective and retrospective data on the resource use, cost and consequences of the PEACH Packages Program (n=75) and usual care (n=95) were collected from three participating local health districts (LHDs) data information systems.
Sensitivity analyses was done to explore the robustness of the cost-effectiveness results to changes in the model inputs and assumptions. Propensity score matching was used to estimate the effects of adding PEACH to usual care adjusting for any differences in key clinical and sociodemographic characteristics in a sensitivity analysis. Where appropriate, the mean incremental net monetary benefit (INB) was estimated at potential threshold values for a unit gain in effect.
Results: Mean costs per patient of providing PEACH (AUD$3,493) in addition to usual care were offset by lower mean inpatient care (AUD$6,392) and emergency department presentation costs (AUD$139). On average, patients receiving PEACH spent an additional four days at home in the last week of life and more died at home (95% vs 49%).
Conclusion: PEACH is a cost-effective model of care when added to usual care for people in the last week of life as PEACH plus usual care is more effective and less costly than usual care alone.

Abstract number: L-09
Abstract type: Poster

Perceptions and Experiences of Early Palliative Care for Patients around the Time of Haematopoietic Stem Cell Transplant: A Qualitative Study

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Background: Early palliative care is increasingly utilised in solid tumour oncology alongside active treatment to improve patients' quality of life. Haemato-oncology patients are often referred later to palliative care despite having significant symptom burden. The time around stem cell transplant (SCT) offers an opportunity to introduce early palliative care, including symptom control, shared decision-making and advance care planning to patients not typically referred to palliative care at a critical point in their care. While studies suggest feasibility and benefits to patients, determining patient views is vital to ensure acceptability to patients.
Aims: To determine patient views and experiences of palliative care around the time of SCT.
Methods: A qualitative study, using a focus group (N=4) co-facilitated by public and patient representatives and interviews (N=12) for patients pre- and post-SCT. Semi-structured interviews were in person, via telephone or via online videoconferencing. Recordings were transcribed and analysed using thematic analysis.
This study was funded by the Hospital Palliative Care Research Fund.
Results: Themes identified were: Perceived needs; Information and decision-making; Importance of relationships; Perception of palliative care; and The future.
Patients pre-SCT had limited direct experience of palliative care, but associated it with end of life care due to indirect experiences and societal views. Once the role of early palliative care was introduced, patients were accepting of it and could see its potential benefits. Patients described many needs around the time of SCT, many of which could be addressed by palliative care.
Conclusions: Palliative care should be integrated with standard care around the time of SCT. Patients should receive open and honest information regarding the role of palliative care. This will allow improved co-working alongside the haematology team and improved quality of life for patients.

Abstract number: L-11
Abstract type: Poster

Adaptation of the Australian Palliative Care Phase Concept to the German Context: A Mixed-methods Approach Using Cognitive Interviews and Cross-sectional Data

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Background: Palliative care phases (stable, unstable, deteriorating, terminal and bereavement) are routinely used in Australia and the UK to describe the clinical situation of patients and their families and to evaluate the associated care plan. In Germany, the concept is not used consistently due to various translations.
Aims: Developing a German version of the palliative care phase definitions by adapting them culturally, and to examine the inter-rater reliability of the adjusted definitions.
Methods (design, data collection, analysis): Mixed-methods approach:

(I) Cognitive interview study using 'think aloud' and verbal probing techniques; analysed using a systematic qualitative analysis approach.
(II) Multi-center cross-sectional study, two clinicians independently assigning the phase definitions. Purposely sampled interviewees in specialist palliative care inpatient units, advisory and community services (I) and three specialized palliative care units with doctors, nursing staff and allied health professionals (II).

Results: 15 interviews were conducted. Identified difficulties were: Some translated terms were:

1) not self-explanatory (e.g. 'family/carer', 'care plan') and
2) too limited to the medical dimension neglecting the holistic approach of palliative care.
3) Problems of comprehension regarding the concept in general occurred, e.g. in differentiating between the unstable and deteriorating phase. Inter-rater reliability was moderate (kappa=0.44; 95% CI=0.39-0.52). The assignment of the phase deteriorating has caused the most difficulties.

Conclusion/Discussion: Overall, the adopted palliative care phases are suitable to use in the German specialist palliative care setting. However, the concept of the phases is not self-explanatory. To implement it nationwide for outcome measurement/benchmarking, it requires further education, on-the-job training and experience as well as the involvement of healthcare professionals.

Abstract number: L-14
Abstract type: Poster

The Impact of Accessible Cancer Care to Enable Support for Survivors (ACCESS) Service Model on Healthcare Utilization Patterns among Breast and Gynaecological Cancer Patients

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Background: Accessible Cancer Care to Enable Support for Cancer Survivors (ACCESS) is a multidisciplinary survivorship care model, that aims to identify and address the varying needs of cancer patients in a large ambulatory oncology centre in Singapore. Patients within ACCESS are triaged using a routine distress screening tool, and those with high distress will be followed up by a supportive care team that provides interventions according to patients' identified needs.
Aim: This study aims to investigate the impact of the ACCESS service model on patients' healthcare utilization patterns.
Methods: This is a retrospective study comparing ACCESS service recipients (N = 1292) to non-recipients (N = 1296) in the same calendar period from 16/9/19 to 16/2/20. All patients were diagnosed with breast or gynaecological cancer. Data were extracted from electronic medical records. Key outcome measures were hospital admissions, length of hospital stay (LOS), visits to the emergency department (ED) and outpatient visits. Categorical and continuous variables were compared using chi-square and Mann-Whitney U tests respectively.
Results: As compared to non-recipients, a lower proportion of ACCESS service recipients had 1 or more hospital admissions (16.2% vs 20.3%, P=0.007), as well as ED visits (10.9% vs 13.4%, P=0.051). ACCESS service recipients also had shorter LOS per hospital admission (3 days vs 4 days, P=0.0016). A larger proportion of ACCESS service recipients attended outpatient cancer rehabilitation and allied health therapy appointments (2.2% vs 0.5%, P<0.001). Outpatient medical (P=0.291), surgical (P=0.377) and imaging (P=0.089) visits were similar in both groups.
Conclusion: The service model instituted appropriate referrals targeting symptoms early upstream. This prevents more severe manifestations in the form of acute healthcare utilization, benefitting both patients and the healthcare system.

Abstract number: L-15
Abstract type: Poster

Palliative Care Needs of Patients with Mesothelioma and their Family Carers: An Integrative Systematic Review

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Background: Patients with mesothelioma and their families have palliative care needs throughout the relatively short trajectory of their illness, from diagnosis to the end of life.
Aim: To describe the palliative care needs of patients with mesothelioma and their families.
Design: Integrative systematic review with narrative synthesis (PROSPERO: CRD42020190115).
Data sources: MEDLINE, CINAHL, PsycINFO and the Cochrane Library were searched for articles published between 01 January 2000 and 10 May 2020. Articles were included if they presented empirical studies or comprehensive reviews including information about the palliative care needs of patients with mesothelioma and their family carers.
Results: The search yielded 508 articles, 14 were included in the analysis. A cross cutting theme of 'uncertainty' was identified encompassing five themes: (1) organisation and co-ordination of services, (2) communication and information needs, (3) management of care needs and high symptom burden, (4) consideration of the impact of seeking compensation, and (5) family caregiver needs. Our findings demonstrate that patients with mesothelioma want a co-ordinated, team-based approach to palliative care with a named point of contact. Whilst carers value and benefit from early referral to specialist palliative care, this does not necessarily reflect the outcomes and views of patients.
Conclusion: The evidence base around the palliative care needs of patients with mesothelioma and their carers needs to be strengthened. The results of this review support the need to develop a greater understanding about the role non-specialist palliative care clinicians' play in providing generalist palliative care for people with mesothelioma and their carers.

Abstract number: L-17
Abstract type: Poster

A National Survey of the Role of Healthcare Assistants in Hospice Out-of-Hours Services

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Background: The majority of out-of-hours (OOH) community-based hospice palliative care services include professionals and healthcare assistants in their teams, although models of provision and skill mix differ. Increasingly, the unregistered healthcare assistant (HCA) is involved in the team, however little is known about their role or contribution to OOH palliative care.

Aim: To describe current UK hospice models of out-of-hours community palliative care, and involvement of HCAs within these models.

Method: An online survey, comprising open and closed items, was sent to managers of 150 UK adult hospices providing out-of-hours services. Questions, adapted from COVPALL (Higginson et al. 2020), concerned service configuration, referral, and staffing. Descriptive analysis was undertaken with quantitative and qualitative data.

Results: 58/150 services (response rate 38%) provided data. Diversity of service models was recorded. The most common OOH service was telephone advice (n=72%), followed by care at home (60%), and Rapid Response (n=35%). Hospices delivering hospice at home service reported that this service was delivered predominantly by HCAs (n=58%); for rapid response, the service was provided mainly by nurses (n=32%), with HCAs (n=19%); and telephone advice was provided by nurses (n=58%), and HCAs (n=21%). Qualitative data suggested that HCAs were a flexible and skilled workforce.

Conclusion / discussion: Findings suggest that hospices provide a range of services that involve HCAs within OOH community palliative care; and that HCAs have played a role in enabling hospices to adapt to increased demand for such services. Further research is required to explore the impact of HCAs within different OOH service models.

Abstract number: L-18
Abstract type: Poster

Do Clinicians' Estimates of Prognosis Impact on Patient Care? A Retrospective Evaluation of Referrals to a UK Hospice Inpatient Unit

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Aim: To evaluate the accuracy and impact of referring clinicians' estimates of prognosis in patients referred to hospice inpatient care.

Methods: Retrospective review of twelve months' referrals to an inpatient hospice unit. Routinely collected data were extracted including demographics, date and source of referral, estimated prognosis, date of admission and death (or date last known to be alive) and preferred place of death. To assess impact, data were collected on: delays to admission; length of stay; place of death; and extent of discharge planning.

Results: 383 eligible patient notes with full datasets were identified. Mean age of 72 years (range 24-101) and majority of referrals received from specialist palliative care teams (365/388: 95.3%).

Prognostic Accuracy: The median (range) survival of patients with a clinician estimated prognosis (CEP) of 'days' (n=141) was 7 (0-164) days; for CEP of 'weeks' (n=167) was 14 (1-538) days; and for CEP 'months' (n=75) was 32 (2-507) days. Kaplan-Meier survival curves showed a significant difference between CEP survival categories of months and weeks ($p<0.0001$); and between months and days ($p< 0.0001$); but not between days and weeks (p= 0.1).

Impact of CEP: The time between receipt of referral and admission increased with increasing length of CEP: CEP days (n=105) median 1 (0-14) days; CEP weeks (n= 154) median 2 (0-46) days; CEP months (n=69) median 3 (0-46) days. No significant difference was demonstrated in the number of discharge planning conversations between groups (0.9 conversations per patient). The proportion of patients achieving preferred place of death was found to be higher for those inaccurately given a CEP of days (19/35: 54%) compared to those inaccurately given a CEP of months (16/47: 34%).

Conclusions: CEP on referral forms affects the prioritisation given to referrals for admission by hospices. Inaccurate CEP on referral forms may influence achievement of preferred place of death.

Abstract number: L-19
Abstract type: Poster

A Survey of Palliative Care Involvement with People with MND/ALS in the UK

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Introduction: The care of people with MND/ALS have often received care from palliative care services – at home and in hospice inpatient units. National guidelines have recommended early involvement and that specialist palliative care should be available as a regular member of the multidisciplinary team(MDT).

Aims: This survey was to ascertain the extent of the involvement of palliative care services in the UK with people with MND/ALS.

Methods: An on-line survey was used, and the details of which were distributed by the Association of Palliative Medicine, which represents doctors working in palliative care.

Results: 86 specialists responded – representing about 40% of specialist palliative care units in the UK. 97% saw MND/ALS patients.

The majority of services (79%) were involved when the patients had specific needs and only a small number were involved only at the end of life or in the terminal stages. There was often collaboration with neurology services (86%), with 60% being part of the MDT. There were few barriers to referral with neurology services not making referrals reported by only 16% and patient or family reluctance to involvement was rare (20%).

Patients with non-invasive ventilation (59%) and tracheostomy ventilation (37%) were often seen. 34% were involved in the care of patients with NIV at home and 96% of services were involved in the discussions of withdrawal of treatment at the end of life.

Discussion: The majority of the respondents were involved in MND/ALS care, although the respondents may be those most involved in this care and may not be representative of the whole of the UK. For the respondents palliative care was often included within the MDT approach. The services were very commonly involved in the care of patients receiving ventilatory support, including advice and support in the difficult, complex and ethical issues of withdrawal of treatment at the end of life.

Abstract number: L-20
Abstract type: Poster

Insights and Awareness Gained by the Self-assesment Tool Palliative Care Aids Organisations to Improve their Palliative Care

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Background: The Dutch national framework for palliative care provides insights into the quality of palliative care (PC). Based on the framework, a self-assessment tool for healthcare organisations (HCO) has been developed. The tool reveals the state of an organisation concerning the organisation of PC and indicates which elements can be improved.

Aims: This study aims at describing the status of 50 organisations that have used the tool for the self-assessment of PC.

Methods: 50 HCO used the digital application of the self-assessment tool. Elements of this tool adress patient care, organisation of PC and collaboration with other organisations. All 50 organisations answered questions and used 10 patient records of the last non-unexpected death patients. Extracted data were analysed both quantitatively and qualitatively by 2 independent researchers.

Results: The self-assessment tool showed that the identification of palliative patients remains difficult for HCO working in different settings. The understanding of what encompasses PC and when it should be introduced varies widely. Some HCO stated that PC should start only in the last 72 hours of life whereas others replied that all clients in a nursing home were labelled as palliative. Furthermore, reporting in patient records varied widely, but significant differences were observed in spiritual, social and psychological dimension of PC.
Conclusion: The self-assessment tool provides HCO insights into the quality of the PC they provide. The analysis of the output shows that internal discussion about PC leads to awareness and insights in its performance, with respect to the topics that need improvement. Areas of improvement encompass the identification of palliative patients and their needs on social, psychological and spiritual issues as well as reporting on the specific care for these patients.

Abstract number: L-21
Abstract type: Poster

Associations between Goals of Care Designation Orders and Health Resource Utilization: A Prospective Cohort Study of Older, Seriously Ill Adults in Acute Care

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Background: Medical order frameworks communicate patients' goals beyond resuscitation, e.g. Goals of Care Designation (GCD) orders describe care focus, interventions and locations through 3 categories (Resuscitative, Medical and Comfort Care) and 7 subcategories. Health resource utilization consequences of GCD are unknown.
Aims: To correlate GCD and resource use during an index hospital admission and evaluate associations between discharge GCD and 30-day readmissions.
Methods: A prospective cohort of 475 acutely hospitalized, seriously ill, older adults were studied (Audit of Communication, Care Planning, and Documentation (ACCEPT) study, 8 hospitals, Alberta, Canada, 2017). Data collected:

(A) patient questionnaire, 2-5 days into admission (demographics and frailty),
(B) patients' medical charts audited at enrolment and 3 months (GCD before admission, at enrolment and discharge, discharge location/death), and
(C) administrative hospital records for 6 months from enrolment (Length of Stay (LOS), Intensive Care Unit hours, Resource Intensity Weighting (RIW), Flagged Interventions (FI)).

Results: Enrolment GCD was associated with all demographic and index admission characteristics, except sex and FI. Patients with Comfort-focused GCD had higher frailty index, more co-morbidities, longer LOS, higher RIW, more FI (almost all related to symptom management), and more palliative care referrals ($p<0.001$). The last recorded GCD was highly associated with death and discharge location ($p<0.001$). Readmission within 30-days occurred for 17% (n=76/436) of discharges. Trends but no significant association was seen between discharge GCD and 30-day readmissions (Medical focused GCD 22%, Resuscitative 15%, Comfort 6%, no GCD 6% readmitted) however discharge location was associated with 30-day readmission.
Conclusion: GCDs appeared appropriately applied and were associated with health resource use during hospitalization and discharge location but not statistically with 30-day readmissions.

Abstract number: L-22
Abstract type: Poster

Predictors of Home Death for Palliative Care Patients Receiving a Nurse-led End of Life (PEACH) Program

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Background: Many people at the end of life prefer to be cared for and, often, die at home. Home palliative care services increase the odds of dying at home, but there is room to improve services to meet preferences. Little is known of factors which influence location of death in people receiving tailored models of care aimed to improve match between preference and actual place of death. The PEACH model of care is a rapid response nurse-led package of care mobilised for palliative care patients who have an expressed preference to die at home.
Aims: To explore association of referral characteristics with separation status at completion of a PEACH package episode of care.
Methods: Prospective cohort study of consecutive PEACH package recipients (Dec 2013 - Jan 2017). Eligibility for PEACH required deteriorating/terminal phase of illness, poor performance status and preference to die at home. Variables included age, gender, carer status, location at referral, primary diagnosis, language spoken and geographic location. The outcome of interest was mode of separation (status of patient at PEACH package episode of care end (discharge, transfer to inpatient care or death)). Descriptive analyses and logistic regression were performed to explore key predictors.
Results: 1,754 clients received PEACH package over study period (Mean age 70 yrs, 55% male). Mode of separation was home death (75.7% n=1327), hospital/palliative care unit admission (13.5% n=237) & 10.8% (n=190) alive and discharged from PEACH program. Of participants with clear preference to die at home at referral (n=1571) 79% met their wish. Cancer diagnosis (OR 1.97, $p=0.003$), preferred home death (OR 6.07, $p<.0001$), & carer relationship (Child/grandchild) (OR 0.57, $p=0.0003$) were significantly associated with mode of separation (home death).
Conclusion: Opportunities to tailor home care based on referral characteristics to meet patient preference to die at home, at individual, system and policy levels exist.

Abstract number: L-23
Abstract type: Poster

Out-of-Hours Care for Patients Nearing the End of Life in the Community and their Families. Systematic Review of Key Processes, Components and Outcomes

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Background: Patients with advanced conditions in the community have complex and fluctuating needs. Yet, little is known about how best to deliver out-of-hours care. This study aims to identify the processes, components and outcomes for 'out-of-hours' community-based care for patients in the last year of life and their families.
Methods: Systematic review using a two-stage search strategy

1) Four databases searched (1990-2019). Studies included primary and/or secondary data on community-based delivery of out-of-hours palliative care.
2) Update of Gomes (2010) Cochrane review to identify trials including home-based out-of-hours palliative care. QualSys criteria were used for quality assessment. Guidelines on palliative care informed the analysis framework, data was narratively synthesised, and a logic model developed.

Results: 121 papers included:1) 87/3260 and 2) 34/2965 papers were identified. Synthesis of qualitative data from a person-centred individual level identified processes of care and patient/family priorities that included symptom management, psychological support, patient safety and the importance of 'being known' to the service. The logic model from synthesis at the orgnaisational level detailed linkage between components of care delivered, intended outcomes (including quality of life, health service use and place of death) and sustainability of care models. Little evidence was identified on effectiveness of models of out-of-hours care.

Conclusions: A novel logic model to understand out-of-hours community-based care has been constructed. Qualitative synthesis identified patient/family priorities for good symptom management, psychological support and effective continuity and coordination of out-of-hours care. However, under-reporting of the different components of care alongside meaningful outcomes is a barrier to the development of the science in this crucial aspect of palliative care delivery.

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Abstract number: L-25
Abstract type: Poster

Trends in Palliative Care Consultation in the Netherlands, from 2004 to 2019: Based on a Nationwide Registry

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Background: In the Netherlands, generalist palliative care (PC) is provided by all healthcare professionals (HCPs) to patients with a life-threatening illness. These HCPs are supported by PC specialists when needed. Since 1998 regional Palliative Care Consultation (PCC) teams were established to enhance the quality of PC and to support all HCPs involved in meeting patients' PC needs.

Aims: The aim of this analysis is to gain insights into the trends and characteristics of Dutch PC telephone consultations in the 2004-2019 period.

Methods: A retrospective analysis was conducted of Dutch PC consultations based on the national registry (PRADO). PCC teams mainly consisted of PC specialized nurses, general practitioners (GPs) and elderly care physicians. In this study, all descriptive and statistical analyses were performed using STATA (version 16.1).

Results: In total 83.899 consultations (annual mean 5.244) were analysed corresponding to 74.143 patients (annual mean 4.634). Most patients were male (51%) and nearly two-third (63%) were 65 years or older. Most (77%) consultations were requested by GPs. Furthermore, pharmacological issues (65%) and pain (44%) were the most registered problems. Overall, the number of consultations per year, has decreased over the past few years. Moreover, consultations regarding patients diagnosed with non-cancer diseases, increased from 9% in 2004 to 24% in 2019. Since 2013 there was a shift in residence of the patient at time of consultation; staying at the hospital increased from 4% in 2013 to 10% in 2019.

Conclusion: The regional PCC teams provide substantial contribution to PC consultation in the Netherlands. There is a trend towards increasing consultations regarding patients with non-cancer diseases, as well as patients admitted to the hospital at the time of consultation. A shift towards increasing collaboration between regional teams and hospital teams was observed, which is in line with the development of more transmural PC.

Abstract number: L-26
Abstract type: Poster

Person-centred Care in Dementia at the End of Life: A Scoping Review and Concept Analysis

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Background: Person-centred care (PCC) is a health and social care priority yet is particularly challenging in dementia at the end of life.

Aims: This review aims to understand and define the concept of PCC for people with dementia at the end of life.

Methods: Scoping review of empirical studies searching MEDLINE, PSYCHinfo, ASSIA, ProQuest, EMBASE, and CINAHL from inception to September 2020. Titles and abstracts were screened individually by JG with any concerns resolved by CE or LS. Full papers were double checked by JG, TW, IT, and CK. Data was synthesised using concept analysis to define PCC, enablers, outcomes and conceptual underpinnings.

Results: From 3492 identified studies, 78 were included. Most studies were from high-income countries (n=75), reporting review (n=23) or qualitative methods (n=22). Components of PCC include; satisfying preferences (n=29); relations with caregivers (n=28); care needs (n=18); acknowledging personhood/individuality (n=14); sensory/bodily interaction (n=12); prior knowledge (n=10); and altering the care environment (n=6). The most often mentioned outcomes were; quality of life (n=19); comfort/agitation (n=12); and caregiver attitudes (n=10).

Discussion: Caring in line with preferences was the main definition of PCC for people with dementia at the end of life. Particular to this context, such care relies on caregivers to support shared decision-making who can acknowledge the person as an individual. As verbal communication is lost, sensory and bodily interactions indicate if care satisfies preferences and needs. PCC in this context is underpinned by Carl Rogers' approach to 'person-centredness' where individuals feel comfort by experiencing themselves reflected in the care they receive. Yet, as death approaches this approach encompasses the attitudes of caregivers, the care environment, and even the wider care system.

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Abstract number: L-27
Abstract type: Poster

Development of a Complex Palliative Care Intervention for Patients with Heart Failure: A Qualitative Study Using the Theory of Change Approach

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Background: Heart failure (HF) patients have significant palliative care (PC) needs but few are provided PC. PC interventions often lack a guiding theory and understanding of their key components and how they interact to achieve an impact. Understanding how and why an intervention works can identify possible barriers and enhance implementation.

Aims: Develop a complex PC intervention for HF patients, describe its key components and demonstrate the causal pathway through which they interact to achieve the impact.

Methods: Intervention development using Medical Research Council framework for developing complex interventions and Theory of Change approach. The intervention was designed in three one-hour facilitated group workshops with stakeholders conveniently sampled from hospital HF specialists from a multidisciplinary team. Using a backward mapping approach, a theory of change map was developed that shows the intervention's causal mechanism.

Results: First, the agreed intervention impact was to meet the holistic PC needs of patients/families. Two long-term outcomes were identified: addressing the basic PC needs of patients/families, and patients/families to feel satisfied. To achieve these outcomes, many preconditions (on a patient/family, health professional and organisational level), intervention activities (educating patients/families/health professionals, assessing PC needs using the Needs Assessment Tool: Progressive Disease-Heart Failure "NAT:PD-HF", collaborating), and contextual conditions (time, relationships, resources) must exist.

Conclusion: The study outlined the mechanism through which a complex intervention works within a specific context and identified the active ingredients necessary for replication. It serves as a model for researchers and policymakers to use. The intervention will be modified after analysing patient/family/health professional interviews on integrated PC before testing its feasibility.

Funding: Lancaster University, British Council

Abstract number: L-28
Abstract type: Poster

iLIVE Project Volunteer Study: Delivery of a Novel Training Programme for Volunteer Coordinators, to Underpin Development and Implementation of Hospital Palliative Care Volunteer Services

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Background: iLIVE is an EU-H2020 funded study to assess end of life care in 13 countries. The iLIVE Volunteer Study (WP3) will evaluate the development, training and implementation of new Hospital Palliative Care Volunteer (HPCV) services for patients in the last month of life, in 5 countries. A European Core Curriculum (ECC) will guide HPCV service development, devised from the results of a recent WP3 Delphi study that identified 54 essential elements for service implementation and training.

Aim: Describe a novel training programme developed for volunteer coordinators (VC's) in use of the ECC prior to developing their own HPCV services.

Design, methods and approach: An educational psychologist with international experience in training volunteers developed the training programme, based in Experiential Learning Theory (ELT). The programme covered the two sections of the ECC:

1. ECC-A: 10-Step Model for development and implementation of HPCV services into a highly structured context (hospital)
2. ECC-B: training curriculum for HPCV's, including example training sessions and materials

Training included plenaries, small group work, guided reflections and participant presentations. Programme evaluation was gained through participant feedback.

Results: 10 participants from 5 countries attended the 3 day training programme. Feedback received was positive and highlighted the following themes:

- The programme provided valuable opportunity for shared learning
- Ongoing reflection via ELT facilitated understanding of the ECC
- A focus on training methodology (including sample training materials) highlighted as valuable

Conclusions: The programme provided a structured, theory-based approach, which facilitated understanding of the ECC, empowering VC's to develop their own HPCV services, and train volunteers to support patients at the end of life. Recent challenges with COVID-19 will impact design and delivery of these services. iLIVE WP3 will evaluate these HPCV services in 5 countries.

Abstract number: L-29
Abstract type: Poster

Palliative Home Care and Emergency Department Visits in the Last 30 and 90 Days of Life: A Retrospective Cohort Study of Cancer Patients

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Objectives: Evaluate the association of specialist palliative home care (HC) on emergency department (ED) visits in the 30 and 90 days prior to death.

Methods: This retrospective cohort study using administrative data identified 6976 adults deceased from cancer between 2008 and 2015, living $\geqslant$ 180 days after diagnosis of cancer, and residing in the urban Calgary Zone of Alberta Health Services. All palliative HC and generalist HC services were examined. Regression analyses examined the relationships of HC type to ED visits in the last 30 or 90 days of life.

Results: In the last 30 days of life, compared to patients receiving palliative HC, patients receiving only generalist HC, or no HC, were more likely to visit the ED (odds ratio $(\mathrm{OR})_{\text{generalist-HC}}$ 1.19; 95%CI 1.06 to 1.34; $\mathrm{OR}_{\text{no-HC}}$ 1.54; 95%CI 1.31 to 1.82). In the last 90 days of life, compared to patients receiving palliative HC, those receiving generalist HC (OR 1.48; 95%CI 1.32 to 1.67) and no HC (OR 1.66; 95%CI 1.39 to 1.99) had increased odds of visiting the ED.

Conclusions: Receiving generalist HC and no HC was associated with increased odds of visiting the ED in the last 30 and 90 days of life, when compared to patients receiving palliative HC. Improving access to palliative HC for patients at high risk of visiting the ED may reduce ED visits and acute care costs and improve quality of life in the last 90 days of life.

Abstract number: L-30
Abstract type: Poster

Dying on the Gastroenterology Ward and Opportunities for Improved Palliative Care

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Background: Many patients admitted in acute gastroenterology wards have complex care needs with variable prognoses and illness trajectories. Little is known about the quality of end of life care in this setting.

Aim: To describe patterns of care for dying patients admitted under the Gastroenterology unit at a tertiary hospital and identify potential areas for improvement.

Method: A retrospective cohort study comprised 65 patients admitted under the Gastroenterology unit who died at a tertiary hospital between 2015 and 2018. Using a validated quality end of life care audit tool, records were reviewed for goals of care discussions, specialist palliative care involvement, admissions to intensive care unit (ICU) and a review of investigations or procedures during the last 48 hours of life.

Findings: Of the 65 patients, 60% were male, average age 62, Charlson comorbidity index 1.47 and length of stay 9 days. No patient had a documented advance care directive though 58% had at least 1 admission in the last year. Deterioration was recognised in 92% of patients, with 89% having goals of care discussions and a documented resuscitation plan during the admission. Nearly half (45%) were admitted to ICU, with 62% of these patients dying there. Most (90%) had at least one invasive investigation or procedure in the last 48 hours of life, with 10% undergoing a resuscitation attempt in the last 12 hours of life.

Conclusion: This study highlighted the absence of advanced care directives documented in the Gastroenterology setting. It also suggests a tendency to focus on curative or life-prolonging measures, as many patients died in ICU, and a majority of patients underwent invasive measures in their last days of life. Despite low comorbidity burden and young age, this study shows the importance and opportunities to integrate advance care planning to improve quality of end of life care in this population.

Abstract number: L-31
Abstract type: Poster

The Current Role of Specialist Palliative Care in Patients with End Stage Liver Disease: A Single Centre Review

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Background: The British Association for the Study of Liver Disease (BASL) recently released a position statement that highlighted the role of specialist palliative care (SPC) in the management of patients with end stage liver disease (ESLD). Their 'Decompensated Cirrhosis Care Bundle' updated in 2020 includes discussion of advanced care planning at an earlier stage.

Aim: The aim of this study was to explore current collaborative practice between medical physicians and SPC to identify areas for further improvement in the management of patients with ESLD.

Method: We conducted a review of patients admitted with ESLD who passed away in a defined time period. We reviewed what percentage received a referral to SPC.

Results: From 2018-2020 we identified 57 patients who matched our criteria, 53% of these were referred to SPC.

Of those who were referred 16% were $<$60 and the median age was 68. Alcohol was the leading cause of cirrhosis (57%) followed by NASH (13%) & other (30%). None of these patients had been listed for transplant. 43% had co-existing hepatocellular carcinoma. 57% had a MELD score of $>$18, indicating a 3-month mortality rate of approximately 20%. 40% of these patients had $>$3 admissions within the last year but only 13% had been referred to palliative care prior to their final admission. Only 1/3 of these patients were under the care of a hepatologist for their admission.

Patients were predominantly referred for end of life care (53%), a third (33%) for symptom management/community input and the remaining (14%) were referred for a separate co-morbidity. 93% of these patients died in hospital in a 2-year period, the other 7% in a home or hospice setting. In 80% of cases the cause of death was a decompensation event.

Conclusion: ESLD is fluctuant in nature and those with a high MELD score have a particularly poor prognosis. All patients passed away in our cohort within 2 years, with the majority dying in hospital. Currently, the role of SPC in these patients is not identified in our hospital guidelines. An update could encourage earlier consideration of the role of palliative care and advance care planning, benefiting the patient and the treating clinician and avoid unnecessary intervention.

Abstract number: L-32
Abstract type: Poster

Developing a "Fast-track" Protocol to Identify and Manage Adult Patients with Palliative Care Needs at the Emergency Department: An Initial Qualitative Study of a Mixed-method Sequential Design

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Background: Protocols to identify and manage adult patients with palliative care needs (APPCN) at the Emergency department (ED) are required to avoid invasive interventions which are often minimally effective and incongruent with patients and caregivers' wishes.

Aim: To explore emergency and palliative care professionals' perspectives about the format and content of a "fast-track" protocol to identify and manage APPCN at the ED.

Methods: Initial qualitative study of a mixed-methods sequential design, involving 7 focus groups with 33 emergency department professionals (31 nurses, 2 physicians) and 5 palliative care professionals (2 nurses, 3 physicians) of an urban central hospital in Portugal (Dec. 2020). Transcripts were subjected to deductive thematic analysis.

Results: A set of indicators was identified about reasons for ED attendance of APPCN and these were dyspnea, pain, confusion, anorexia, food refusal, bowel obstruction and family burnout. Participants recognised that some interventions done to APPCN at the ED (e.g. diagnostic tests) represent suffering or are futile. All recognised the presence/involvement of family/carers as important. None of the ED professionals were used to consult patient data to know if there was an anticipatory wish or will registered to act in consonance, but all recognised this was important, to align patients' goals of care with the care they receive. Participants made suggestions regarding the format of an APPCN identifier for accessing the "fast-track" protocol at the ED, namely a letter, a wristband, a palliative care alert card or an alert in the clinical data system.

Conclusions: The reasons for ED attendance of APPCN, interventions that should and should not be done and other indicators such as family/carer presence and involvement must be considered in the construction of protocols to treat APPCN in an ED setting. The next step is a Delphi consensus with experts, with the aim of refining a shared set of indicators.

Abstract number: L-33
Abstract type: Poster

Review of Treatment Escalation Plan (TEP) Documentation in a Specialist Palliative Care Unit

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Background: Treatment escalation plans (TEPs) are a vital tool for planning care particularly in a palliative care setting. They should be documented with the patient's current clinical condition and likely disease trajectory in mind and should be reviewed regularly.

Aims: In this review we aimed to evaluate our current practice in documenting TEPs and to assess whether our current TEP template is fit for purpose.

Methods: We used mixed methods including chart review and staff survey.

We have generated descriptive statistics and performed a content analysis of free text survey answers.

Results: 93% of patients had a TEP documented within 24 hours of admission. However, only 47% had a TEP which clearly documented whether the patient was for escalation of care/transfer to the acute hospital or not. Only 7% of TEPs mentioned suitability for IV antibiotics and only 13% included documentation regarding need for regular vital observations. 82% of nurses and 50% of doctors thought the current free text TEP template was fit for purpose. 64% of doctors and 67% of nurses felt the current TEP form lacked essential information 'some of the time'.

Themes from free text survey answers included a need for, 'more regular review of the TEP form when a patient's condition changes' amongst nurse respondants. Doctors highlighted a need for 'more prompts for important elements' including appropriate ceiling of care, whether for acute hospital transfer if deteriorating, whether for IV or PO interventions and if regular vital observations were required.

Conclusion/discussion: Although the majority of patients have TEPs documented within 24 hours of admission, the content of TEPs could be improved. While many staff members felt the current TEP is fit for purpose, the survey revealed a number of suggestions regarding how the template could be improved. This work also contributed to a hospital wide Quality Improvement Project on TEP documentation leading to rollout of new forms.

Abstract number: L-34
Abstract type: Poster

Development and Implementation of a Transmural Palliative Care Consultation Service: A Multiple Case Study in the Netherlands

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Background: In the Netherlands, healthcare professionals attending patients in the last phase of life, can consult an expert palliative care team (PCT) in case of complex problems. There are two types of PCTs: non-hospital and hospital PCTs. Integration of these PCTs is expected to facilitate continuity of care for patients receiving care in different settings.

Aims: We studied facilitators and barriers in the process of developing and implementing an integrated transmural palliative care consultation service.

Methods: A multiple case study was performed in four palliative care networks in the southwest Netherlands. Researchers were closely observing the process within project teams. A within-case analysis was conducted for each network, using the Consolidated Framework for Implementation Research (CFIR). Subsequently, all findings were pooled.

Results: In each palliative care network, project team members thought that the core goal of a transmural consultation service is improvement of continuity of palliative care for patients throughout their illness trajectory. It was nevertheless a challenge for hospital and non-hospital healthcare professionals to arrive at a shared view on goals, activities and working procedures of the transmural consultation service. All project teams experienced the lack of evidence-based guidance on how to organize the service as a barrier. Different financial reimbursement systems for hospital and non-hospital care made implementation of the service complex. Three networks managed to develop and implement a transmural service at some level.

Conclusions: Healthcare professionals are motivated to collaborate in a transmural palliative care consultation service. However, they need more guidance in defining views and on organizational issues, as well as appropriate financing. Further research is needed to provide evidence on benefits and costs of different models of integrated transmural palliative care consultation services.

Abstract number: L-35
Abstract type: Poster

A Systematic Review of the Effectiveness of Person-centred Interventions for Serious Physical Illness in Terms of Self-report Outcomes and Costs

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Introduction: Serious illness carries a high risk of mortality, negatively impacts quality of life (QoL) and daily function, and is burdensome in symptoms. No review to date has aimed to integrate the evidence across serious illness. We aim to review the evidence for interventions that aim to deliver person-centred care (PCC).

Methods: Systematic review of literature using PRISMA guidelines. We searched Amed, Assian, CINAHL, Cochrane Library, Embase, Medline, PsycInfo, Scopus and Web of Science data bases. We used the following key concepts, PCC, family-centred care, family-based care, individualised care, holistic care, value-based care.

Results: We screened 4792 papers and 65 papers (reporting 51 different studies) were retained in the review. 41 studies were RCT's, the remainder were pre and post/before and after design. We synthesised findings across two main categories: 1) Studies with self-management components and 2) technology-based interventions.

Self-management component. These were conducted in COPD, T2D elderly with chronic conditions, cancer, IBD, and multi-morbidity populations. The interventions consisted of training of patients and/or caregivers or staff. Sessions were either group-based, or individualised. Reduction in hospital admissions, costs of care and improvement in QoL were significant across most studies. Self-efficacy and knowledge were not significant across most studies.

Technology based interventions: COPD T2D, cancer, elderly, and IBD populations reported using technology (phone, mobile app, tablet/computer, and video). The outcomes however varied across these studies. Self-efficacy, hospitalisations/rehospitalisations, and length of stay were significant across most studies. QoL was not significant across most studies.

Conclusions: PCC interventions using self-management or technology are effective in improving QoL, self-efficacy, reducing hospitalisations, and costs. PCC approach is needed in the management of serious illness.

Abstract number: L-36
Abstract type: Poster

Trends in Specialist Palliative Care Services in an Urban Teaching Hospital over 5 Years

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Background: The palliative care "minimum data set" (MDS) is a national survey of patient activity data for specialist palliative care services in Ireland and is vital to strengthen the quality of service provision. However, the MDS data from acute hospitals has not been published or made available to service providers.
Aim: To determine the trends in specialist palliative care services in an acute hospital setting over 5 years
Methods: Data was collected from the minimum data set for an urban acute hospital service from 2015-2019, with additional information, including Palliative Performance Scale (PPS) and timing of patient referral and patient outcome, collected from a second database.
Results: There were 485 new inpatient referrals and 73 new outpatient referrals in 2019, an increase of 25% and 20% respectively from 2015. In 2019, the proportion of non-cancer patients was 47% for new inpatient referrals and 12% for new outpatient referrals. 47.5% of non-cancer patients were seen in the last week of life, compared to 11.9% of cancer patients. Over 40% of non-cancer patients had a PPS of 10% on first review, compared to 6.9% of cancer patients.
Conclusions: The demand for specialist palliative care services in the acute hospital setting is increasing, with resultant implications for service planning. The marked difference between cancer and non-cancer cohorts suggests that the expansion of palliative care in the acute hospital setting into non-malignant diagnoses predominantly involves end of life care. Earlier referrals might provide opportunities to impact more on symptom management and advance care planning but effecting this type of change is challenging and demands resources. Finally, the lack of publication of the MDS data from acute hospitals may be a lost opportunity to identify trends, best practice and scope for improvement.

Abstract number: L-37
Abstract type: Poster

Multi-professional Palliative Care Team Can Contribute to Better Care

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Background: Multi-professional palliative care teams (PCT) are increasingly available for counseling for units that do not work with specialized palliative care. In order to evaluate the consulting team's work, a questionnaire survey was conducted, aimed at staff in hospital units with regular palliative counseling rounds. The questions considered the PCT's availability and whether relevant advices were given resulting in better care for patients.
Method: A case study of a PCT at a University Hospital in Sweden was conducted. The team was composed of three professions, physician, nurse and social worker and has existed since 2016. An online survey was designed and sent to the units that have or have had regular rounds with PCT. A descriptive analysis was performed.
Results: Those who responded (n = 49) were mainly physicians and nurses, evenly distributed between the professions. Participating clinics were mainly medicine clinic and surgical.
The majority considered that the consulting team had good accessibility, provided relevant advice and contributed to better care for the patient. It was found an advantage that the team consisted of different professional categories. The contact with PCT took place mostly through fixed-term rounds and through telephone calls.
Although most considered the PCT's advices to be valuable, relatively few contacted the team outside of regular business hours. Just under half clearly understood what the consulting team could help with.
Discussion: PCTs working with regular rounds seems a prerequisite for a recurring and well-known consulting business. Less than half of the participants seemed to have a clear idea of what the palliative care team can help with. This may be due to the fact that many people still associate palliative care with the very last days of life and that the benefits of early integration, in the form of palliative counseling and symptom relief that the consulting team can contribute, are not yet widely known.

Abstract number: L-38
Abstract type: Poster

Early Integration of Specialised Mobile Palliative Unit for Patients with Newly Diagnosed Lung Cancer

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Background: Survival benefit of early paliative care (PC) for advanced lung cancer (ALC) patients (pts) has been well documented. The largest Slovenian University Hospital for pulmonary diseases University Clinic Golnik (UC Golnik) diagnoses around 40% of lung cancer pts. Newly diagnosed ALC pts, not eligible for any kind of oncological treatment, living in the north-western Slovenia, are referred to specialised Mobile Paliative Unit (MPU) operating in that region for home care.
The aim of our analysis was to evaluate the burden of interventions of MPU, number of hospitalisation and pts place of death.
Methods: It is a single center retrospective study. All pts with newly diagnosed ALC at UC Golnik not eligible for any kind of oncological treatment, from February-December 2020, were included in the study. Data were obtained from pts charts. We analysed time from referral to MPU first home visit, number of MPU home visits and MPU telephone calls, number of hospitalisatons and place of death.
Results: 27 pts were included in analysis with median age of 72 years (56-91), most were male (67%). Median time from referral to first MPU home visit was 18 days (0-126). Patients were followed by MPU on average for 77 days (2-340). Median number of MPU home visits was 3 (range 1-23), median number of telephone calls was 4 (1-10). 21/27 pts died in the observed period, except for one, all at home.
Conclusion: Concept of cooperation between University Hospital and MPU is new in Slovenia. Palliative care in Slovenia is still in development with little attention given to home care. For pts with ALC, it has been feared that due to high simptom burden, home care cannot be made possible and oncologists were reluctant to discharge patients in home setting.
In our analysis we showed that early referral to MPU enables pts to stay and die at home.
These results may help to promote such concept of of palliative care in Slovenia and give more importance to home care as well.

Abstract number: L-40
Abstract type: Poster

End-of-Life Care in Burn Intensive Care Units: A Systematically Conducted Scoping Review

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Background: Burns are a serious illness with significant consequences for patients, families, healthcare teams and systems. End-of-life care and decision-making in burn intensive care units (BurnICUs) are challenging, although rarely studied.

Aim: To review and synthetize the evidence on end-of-life in BurnICUs about the characteristics of end-of-life in BurnICUs, symptom control provided to burned patients facing dying and death in this context, and the concepts, models and designs of the care provided.

Methods: Systematic scoping review, following Arksey and O'Malley's framework. PRISMA was used as reporting guideline. Searches were performed in three databases; no time restriction, up to July 2020.

Results: 12.926 documents identified; 11 selected for analysis and synthesis. Three key themes emerged: (i) characteristics of the end-of-life in BurnICUs, including end-of-life decisions, decision-making processes, causes and trajectories of death; (ii) symptom control at the end-of-life in BurnICUs; (iii) concepts, models, and designs of the care provided to burned patients at the end-of-life, mainly care approaches, provision of care and palliative care (PC).

Discussion/ conclusions: End-of-life care is a major step in the care provided to critically burned patients. Dying and death in BurnICUs are often preceded by end-of-life decisions, namely forgoing treatment and do-not-attempt to resuscitate. Different dying trajectories were described, suggesting the possibility to develop further studies to identify triggers for PC referral. Symptom control was not described in detail. PC was rarely involved in end-of-life care for these patients. This highlights the need for early and high-quality palliative and end-of-life care in the trajectories of critically ill burned patients, leading to an improved perception of end-of-life in burn BurnICUs. Further research is needed to study the best way to provide optimal end-of-life care and foster integrated PC in BurnICUs.

Abstract number: L-41
Abstract type: Poster

Palliative Nursing for Cardiac Patients – A National Review of Hospitals' Clinical Practice Guidelines

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Background: Palliative nursing is recommended to patients with critical heart disease throughout the illness trajectory. However, the extent to which Danish cardiology departments have undertaken palliative nursing are unknown.

Aim: To review clinical practice guidelines from Danish hospitals on palliative nursing for cardiac patients.

Method: We conducted a systematic search in databases for hospitals in the five Regions of Denmark for clinical guidelines produced or revised in 2015-2020. Full–text guidelines were assessed against eligibility criteria and data on content was extracted.

Results: Across hospitals in all five Regions 24 out of 70 guidelines originated from departments of cardiology, 13/24 was built on scientific evidence. There was a predominant focus on terminal care (19/24), on identification of symptoms and pharmacological treatment (17/24). In 7 out of 24 guidelines we found specific descriptions of nonpharmacological nursing interventions and early palliative care was identified in five. Of the remaining 46, 25 were published by palliative care units. The prevalent tool to identify symptoms was EORTC-qlq-15-PAL (3/24 and 12/25), but there was a lack of guidance on its use. Social needs were mentioned in 15/24 guidelines with focus on applying for medicine subsidies. Support for caregivers was addressed in 19/24 guidelines however, the support was defined to be outside the hospital. Furthermore, the review uncovered a limited focus on cross-sectoral cooperation (3/24).

Conclusion: Clinical guidelines on palliative nursing in a cardiac department were found in all the Danish regions, but with great variation and a dominant focus on clinical symptoms and terminal care. The review revealed a need to improve guidelines on how to apply nursing interventions in practice. It also revealed a need for a stronger base in scientific evidence. The variations across hospitals suggests a need for a national guideline on palliative care for the cardiac patient.

Abstract number: L-42
Abstract type: Poster

From Urgent to Appropriate Care: The Integration of Paramedical Services in the Provision of Community Based Palliative Care, Improving People's End of Life Care at Home

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Background: Ambulance paramedical staff, when called upon by consumers, are seen as trusted community focused health care providers. Guidelines and tools are available for paramedics to extend this role to support peoples' anticipated end-of-life care at home. Significant barriers and gaps in their utilisation have been identified, with poorer consumer outcomes.

Aims: This project sought to develop and validate a set of working principles, to provide the basis for the systematic integration of paramedical services into community-based palliative care services across Victoria, Australia.

Methods: Underpinned by the Institute for Healthcare Improvement's Model for Improvement methodology, a project Expert Working Group (EWG) came together to investigate and determine by consensus, the key change ideas that could be themed to drive change for enhanced organisational relationships, more effective communication of processes and pathways of care, and better ability for paramedics recognition of a person and caregiver needs that could be appropriately responded to.

Results: A twenty member EWG was formed, representative of sector experts, to successfully assist with the development of an issues scoping report, reach consensus on key principles of engagement between Ambulance Victoria paramedics and community palliative care providers, contribute to the development of the initial pilot program, with outcome, process and balance measures being tested within selected services and establish an ongoing program of related improvement activities.

Conclusion: Preliminary evaluation demonstrated that the Model for Improvement methodology, with the achievements of the Expert Working Group, provided the catalysts for the systematic integration of paramedical services with the work of community palliative care services. The capability of services to respond more effectively to a person's palliative care needs could be met and an ongoing program of improvement work established.

Abstract number: L-43
Abstract type: Poster

Implementing Outcome Measurement and Individual Care Planning in Specialist Palliative Care: An Education and Support Programme in Italy

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Introduction: Outcome measurement (OM) and individual care planning remain poorly developed processes in Italian specialist palliative care services (SPCS). The Integrated Palliative Care Outcome Scale (IPOS) and other measures suggested by the OACC collaboration are now translated and available for clinical settings. The Italian Society for Palliative Care (SICP) supports this initiative and encourage its associates to participate and implement this activities.

Methods: A structured educational course is offered to Italian SPCS.
The course is made of 3 modules and a follow up session:

- A first 8 hours day module, involving all the members of the SPCS team, introduces the IPOS and other measures of the OACC suite (Phase of Illness, AKPS and the ZBI short version)
- A 3 months field experience phase, where all the members of the SPCS teams use the tools in an experimental environment
- A final module, where participants discuss pros and cons of their experience and receive advice on implementation
- A follow up module involving managers of the SPCS is offered after 6 to 12 months from implementation to improve specific outcomes and tackle organizational issues

Results: In 2 years 7 SPCS in Italy and 1 in the Italian speaking region of Switzerland received the course. A total of about 550 members of the SPCS attended the course. The overall acceptance of the programme was defined as good to very good by most of the attendees. IPOS was chosen as main OM tool by the participant SPCS and is now going to be proposed as a standard at regional and national level. SICP is promoting this process by offering specific training session during the last two national conferences to selected delegates.

Conclusions: IPOS is a valid and useful OM for clinical practise. Its implementation in SPCU is eased by the concurrent use of the other OACC collaboration tools. The individual care planning based on needs assessed with IPOS, allows the measurement process of the outcomes reached by the SPCU.

Abstract number: L-44
Abstract type: Poster

Lessons Learned in Canada: Successful Uptake of Advance Care Planning Indicators

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Background: In 2014, a province-wide policy for advance care planning (ACP) and Goals of Care Designation (GCD) was implemented across Alberta. Nine performance indicators in relation to ACP/GCD policy have been developed and used to populate an online Alberta ACP/GCD dashboard using Tableau software. Nevertheless, it remains unknown how these indicators and the dashboard are used.

Aim: Our study is the first to systematically develop, implement and evaluate performance indicators in relation to ACP/GCD policy.

Methods: A convenience sample of the ACP/GCD Community of Practice in Alberta was invited to participate in an anonymous online survey. The survey included a validated usability questionnaire for the dashboard, the System Usability Scale (SUS).

Results: Eighteen out of 33 members answered the survey (a 54.5% response rate). Half of the respondents had held a leadership or management role for ten years or longer. Reported rates of staff ACP/GCD training were low; only 27.8% and 22.2% respondents had over half of their staff trained via e-learning modules or in-person workshops, respectively. Most respondents (55.6%) had access to Tableau while they had used various ACP/GCD audit resources. The mean SUS score was 70.8, which was above the threshold of being acceptable (70.0). Over half of respondents (61.5%) found the indicators informative and meaningful for their practice and about half (46.2%) were willing to use the dashboard and/or indicators to change their sites' ACP/GCD practice. Four overarching recommendations emerged from content analysis in relation to current experiences of delivering ACP: congruency, auditing, awareness and education.

Conclusion: The nine indicators and the dashboard were acceptable and usable for monitoring performance in the rollout of ACP/GCD. Lessons learned in Alberta provide a model for transforming data into actionable information on performance metrics, which has the potential to improve frontline ACP activities.

Abstract number: L-45
Abstract type: Poster

Patient, Family Carer and Staff Perspectives on the Impact of Enhancing 7-day Specialist Palliative Care Services: A Qualitative Study

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Background: Some specialist palliative care (SPC) services can have restricted availability at evenings and weekends. This potentially has a detrimental effect on patient and family experiences, and care outcomes, such as emergency hospital admissions. Understanding whether extending (increased hours) and enhancing (more qualified staff) has an impact on such outcomes is important.

Aims: To evaluate the effect of extended and enhanced 7-day SPC services, and explore a range of perspectives on these services.

Methods: Qualitative thematic analysis drawing from semi-structured interviews with patients, family carers and service staff using or delivering enhanced specialist palliative care across two sites (incorporating acute hospital, hospice and community services) in the UK. Participants were purposively selected as key informants, or likely to have rich experiences. Data were collected in 2019-20. Thematic analysis involved detailed analysis of full-text transcripts. Full research ethics and governance approvals were given.

Results: Patients (n=19), family carers (n=23) and staff (n=33) participated across both sites. Impacts of the enhanced 7-day services were felt across five areas: Responsiveness (of staff / service); Reassurance (for patients, families and staff); Relationships (between staff and patients, and between staff); Reciprocity (between staff and patients, and between staff); and Retention (of more satisfied service staff). Uncertainty and fear experienced by patients and family carers were ameliorated by the enhanced service. It was also positively viewed by staff within and outside SPC.

Conclusion: Enhanced 7-day SPC services have impact, and should be developed further to promote high quality integrated care for patients and families. The team enacting new models of care are central to success, with staff development and retention key considerations when developing similar models.

This study was funded by Macmillan Cancer Support.

Abstract number: L-46
Abstract type: Poster

Development of Quality Measurement Tool for Hospice Care in the Czech Republic

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Aim: The aim of the project was to develop a complex tool for measuring the quality of hospice care in the Czech Republic which would be used

either by community or by inpatient care provider. Along with the development and professionalisation of the hospice and palliative care in the Czech Republic, there is an increasing need to monitor the service quality and provided care.
Methods: The tool was designed by an expert research group consisting of representatives of community and inpatient hospice care providers and palliative care researchers. Over the period of one year subsequent strategy meetings were organized to

(i) determine the set of quality indicators and
(ii) prepare a questionnaire for bereaved caregivers of hospice patients.

A consensus method was used to develop the standardized tool. In the first phase the expert group made an inventory of actually reported relevant quality indicators. In the second phase, guided by the literature and evidence based practice, the expert group developed a new set of quality indicators. For the candidate indicators, the expert group assessed their feasibility, importance and sensitivity to change. In the third phase the final set was established. Paralelly the questionnaire was consensually agreed, then piloted with 15 bereaved caregivers and 8 hospice workers.
Results: As a result (i)a set of quality indicators for hospice palliative care has been developed and (ii)a questionnaire for bereaved informal caregivers of hospice patients measuring quality of hospice care was designed. Both tools reflect the recommended quality standards of palliative care.
Conclusion: This is the first standardized tool for measuring the quality of hospice care which was developed within the Eastern European region. The tool is currently being piloted in 5 hospices.
Funding: This work was supported by a grant from Nadace Komerční banky, a.s. – Jistota, a private foundation supporting palliative care initiatives in the Czech Republic.

Abstract number: L-48
Abstract type: Poster

Trends in End-of-Life Indicators among Patients Dying in University Hospital Oncology Ward after Implementation of Palliative Care Unit

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Aims: To assess the trends in end-of-life indicators among patients dying in university hospital oncology ward before and after the implementation of palliative care unit.
Design: The study population consists of all patients who died in Kuopio University Hospital oncology ward at 1.1.2010 – 31.10.2011 and 1.1.2012 – 31.12.2018. The palliative care outpatient clinic was established between these dates. The data on the inpatient stays, cancer treatments, treatment decisions and some background factors were retrieved from the electronic patient records.
Results: The study population totaled 644 patients (57.5 % males; 42.5 % females) who died of cancer in the North-Savo Health Care District in 2010 - 2018. Of all the patients who died of cancer in the district, 17.2 % (191/1108) in 2010 – 2011 and 11.1 % (461/4049) in 2012 – 2018 died in the oncology ward of the university hospital. In years 2012 - 2018, 14.1 % of patients visited the palliative care unit. The percentage of DNR (do not resuscitate), palliative care and end-of-life decisions increased significantly between the periods (table). The decisions were mainly made during the last week of life. The proportion of patients receiving chemotherapy during the last two weeks of life remained stable.
Conclusion: The proportion of patients receiving DNR, palliative care and end-of-life decisions increased after the implementation of the palliative care unit, but they were still made rather late, during the last days of life.

	Years 2010-2011 (n=183)		Years 2012-2018 (n=461)		p-value for difference
	n / median	%/ range	n / median	%/ range	
DNR decision	28	15.3	377	81.8	*< 0.001*
Time from DNR decision to death (days; median)	6.5	0-515	6	0-1264	ns
Palliative care decision	122	33.2	246	66.8	*0.005*
Time from palliative care decision to death (days; median)	7	0-382	8	0-1761	ns
End-of-life decision	100	54.6	307	66.6	*0.007*
Time from end-of-life decision to death (days; median)	2	0-128	2	0-31	ns
Inpatient days in last six months of life (median)	22	1-108	16	1-138	*< 0.001*
Receiving chemotherapy in last 14 days of life (patients)	13	7.1	46	10	ns

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Abstract number: L-50
Abstract type: Poster

A Qualitative Study on Palliative Care Nurses' Experiences on the Use of Subcutaneous Medications and Subcutaneous Infusions via Syringe Driver at Home

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Background: Prescribing subcutaneous medications for use in patients' homes and initiation of continuous infusions via syringe driver is an important aspect of community palliative care service delivery. It is common practice in palliative care to use non-oral routes to provide optimal symptom control for patients, mainly when other administration routes are inappropriate, ineffective, or simply unavailable. Palliative care nurses in the community are responsible for providing subcutaneous medications and starting subcutaneous infusions via syringe driver at home. Their views and experiences will provide new, vital information to improve the quality of palliative care service delivery at home.
Methods: A qualitative study using focus group, conducted with palliative care nurses from a hospice in Kuala Lumpur, Malaysia. Ten participants were recruited. Discussions were transcribed verbatim and analysed thematically.
Results: Five main themes emerged

(1) System enablers
(2) Acquirement of complex skills
(3) Specific community palliative care related challenges and potential strategies to overcome them

(4) Unmet needs of palliative care nurses
(5) Role of palliative care nurse as an advocate and educator.

Conclusion: Delivery of subcutaneous medications and subcutaneous infusions to palliative care patients at home requires a system that supports the clinical, educator and advocacy role of palliative care nurses. Palliative care nurses need to be better supported because the use of subcutaneous medications and subcutaneous infusions involves a complex decision-making process with unique challenges specific to delivering palliative care to patients who wish to be cared for at home. Further research is needed to examine patients and caregivers' experiences on the use of subcutaneous medications and subcutaneous infusions to better inform palliative care service delivery in the community.

Abstract number: L-51
Abstract type: Poster

Using IPOS to Measure Longitudinal Effect of Enhanced Supportive Care - What Interval Is Ideal?

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Aim: To retrospectively explore changes in IPOS score among a mixed cancer population and describe a suggested timeline for measurement.
Method: We retrospectively audited IPOS scored collected during the 2019-2020 CQUIN year for a mixed cancer population. Median change over time for each symptom was plotted and compared with baseline. Mann Whitney U test was used to analyse differences in scores for non-parametric data to determine time points most likely to show a change from baseline in order to recommend a frequency for future monitoring.
Results: Of 275 patients included in the CQUIN, 233 have completed IPOS Scores. The most common physical symptoms at baseline were weakness (158), pain (156) and poor appetite (117). The presence of psychological, information and practical needs were more common. Clinically and statistically significant reductions in IPOS score were apparent at first follow up. However, the greatest median reductions in weakness, pain and poor appetite compared to baseline was seen after 4 follow up appointments. Peak improvement in anxiety scores (median change 1 point reduction) was also seen at this point.
Conclusion: Whilst clinically important reductions in IPOS score are seen after 1 appointment with ESC, the peak effect is later than initially suspected. This finding informs national discussions about when to measure impact of ESC using IPOS.

Abstract number: L-52
Abstract type: Poster

The Impact of Enhanced Supportive Care on the Nature of Non-elective Admissions for Patients with Hepatobiliary Cancer

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Background: There is growing evidence supporting the value of Enhanced Supportive Care (ESC) services for patients with cancer, but long term funding requires evidence of financial sustainability. Many centres are aiming to measure this by focusing on patients with tumours which traditionally involve high proportions of unplanned admissions and prolonged lengths of stay. Our centre aims to be the first to publish robust data in the hepatobiliary (HPB) cohort.
Aim: To evaluate the impact of ESC on the unplanned admissions and lengths of stay for patient with HPB cancer.
Method: We retrospectively evaluated the outcomes of 101 patients with HPB cancer seen in our ESC service over three years. We compared the number of unplanned admissions and lengths of stay in the last year of life for these patients against the national averages for HPB patients contained within the NHS Digital Secondary Uses Service (SUS) dataset. To counteract selection bias in our sample, we compared the median survival against an equally sized control group who did not attend ESC but in whom factors which are known to affect prognosis were controlled: tumour type and histology, surgery, chemotherapy regime, performance status, age and site of metastases.
Results: Survival between the ESC and Non ESC group was not statistically different; indicating once prognostically influential factors were controlled, the ESC group was not more or less 'unwell' than would be expected for the tumour group. Unplanned admissions for the ESC group in the last year of life was 1.61 per patient with average length of stay of 5.49 days. The national average for HPB patients in England is 2.57 admissions per patient and 9.1 days average length of stay.
Conclusion: For 101 patients with HPB cancer who attended ESC, 97 unplanned admissions in the last year of life were avoided and average length of stay reduction totaled 534 days.
The financial impact of this using commissioner reference costs is a saving of £668,576.30.

Abstract number: L-53
Abstract type: Poster

Palliative Rehabilitation - Bridging the Gap from Acute Hospital to Specialist Palliative Care (SPC) Community Services

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Background: Rehabilitative Palliative Care (RPC) is under-developed in Ireland. The Department of Health provided funding for a 6 month pilot of a novel RPC service comprising of a hospital-based SPC occupational therapist (OT) and a community-based SPC physiotherapist (PT) who integrated care across settings. The service commenced in February 2020 but paused in March due to the pandemic(Phase 1). Services resumed in September 2020(Phase 2).
Aims: Our longitudinal mixed methods case study aims to explore the place of a novel RPC service in SPC. This abstract describes the profile and usage of patients accessing home-based RPC during Phase 2.
Methods: Patient survey and chart review. Data were collected prospectively over18-weeks service provision and analysed using descriptive statistics.
Results:179 patients received care; 106 in hospital, 49 at home and 24 received care in both locations. 15 patients outside the catchment area were unable to avail of RPC at home. Preliminary analysis of 67 patients found the majority of patients had a cancer diagnosis (n=47), followed by advanced respiratory disease(n=11), advanced cardiac disease(n=5) and advanced neurological conditions (n=4). The average age was 71.9 years(range 43 – 100). The median Australian modified Karnofsky score was 50%(30 – 70%) and median RUG ADL was 5(4 – 18).

Table 1. lists the reasons for completion of the service.

Deterioration/Death	19
Ongoing care	15
Goals achieved	12
Declined service	12
Referred for ongoing SPC rehab in established programme	3
Cognition limiting engagement	1

Discussion: Deterioration in patients' medical condition, while inevitable in SPC services, challenges the ability to provide a rehabilitation service. However, with RPC some patients achieved their goals. Further analysis may help identify those able to actively engage in rehabilitation.

Abstract number: L-54
Abstract type: Poster

Comparing the Effect of a Consult Model versus an Integrated Palliative Care and Oncology Co-rounding Model on Healthcare Utilization in the Acute Hospital – A Stepped Wedge Cluster Randomized Trial

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Background: While the benefit of specialist palliative care for cancer inpatients is established, the question of how best to deliver palliative care is still unknown.
Aims: To compare the current Consult model versus an integrated Co-rounding model of palliative care and oncology care; both provide the same content of palliative care but with different formats of delivery.
Methods: Cluster-randomized trial with stepped-wedge design of cancer patients admitted to an acute hospital. Primary outcome was hospital length of stay; secondary outcomes were proportion of admission who were readmitted within 30 days of discharge and access to palliative care. ClinicalTrials.gov number NCT03330509.
Results: A total of 5681 admissions in 4 clusters from December 2017 to July 2019 were included. Adjusted for time period and cluster of admission, admissions under integrated Co-rounding model had a hospital length of stay shorter than that of admissions under Consult model by 0.70 days for all admissions (-0.70 days, 95% CI -1.45 to 0.04, p-value=0.065) and 2.62 days in the subgroup of admissions who received palliative care (-2.62 days, 95% CI -4.61 to -0.63, p-value=0.010). Hospital readmission within 30 days (OR 1.03, 95% CI 0.79-1.35, p-value=0.822) and access to palliative care (OR 1.19, 95% CI 0.90-1.58, p-value=0.215) were similar between Consult and Co-rounding model.
Conclusion: The Co-rounding model was associated with shorter hospital length of stay. Readmissions within 30 days and access to palliative care were similar. The context within which palliative care services are delivered has an effect on patient outcomes such as hospital length of stay.

Abstract number: L-56
Abstract type: Poster

Is It Possible Ho Integrate Palliative Care in Burn Intensive Care Units? Results from a Qualitative Study with Healthcare Professionals

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Background: Burn intensive care units (BurnICUs) are intensive care units specialized in the care of critically burned patients. Palliative Care (PC) is applicable in BurnICUs.
Aims: To understand healthcare professionals' perspectives about integrating PC in BurnICUs.
Methods: Qualitative study with in-depth interviews. All 5 reference centres of BurnICUs in Portugal were invited to participate; 3 participated. 15 professionals (12 nurses and 3 physicians) were interviewed from July to October 2020, until reaching theoretical saturation. A thematic analysis was performed to interview transcripts.
Results: Three themes emerged: Concept of PC; Potential impact of and Barriers and Facilitators. Professionals perceive PC either as end-of-life care or rehabilitation care. They consider that PC provides pain control and suffering relief, improving patients' quality of life (QoL). All participants agreed that PC could be integrated in BurnICUs but lack ideas on how to do it. Three barriers were identified: (i) patients' condition, characterized by high degrees of uncertainty, as serious burn injuries are associated to hemodynamic instability and highly technical procedures that may aggravate pain and suffering; (ii) characteristics of BurnICUs, which might compromise PC philosophy and practices, particularly due to restricted access and visiting policies because of the high risk of infection; and (iii) teamwork dynamics of BurnICUs, making collaboration between professionals working in BurnICUs and PC difficult. Some facilitators were highlighted, namely the outcomes of PC integration: improving patients' QoL and quality of care.
Conclusions: PC in BurnICUs is perceived either as end-of-life care or rehabilitation care. This shows the potential for integrating PC in BurnICUs. While professionals identify barriers for the integration of PC in this setting, they recognise facilitators and opportunities to foster this integration.

Abstract number: L-57
Abstract type: Poster

Strategies for Knowledge Translation of a Palliative Approach Outside Specialized Palliative Care Services: A Scoping Review

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Goal of the work: Integration of a palliative approach across populations and healthcare services is needed. The aim was to map strategies for knowledge translation of a palliative approach to care into non-specialized palliative care services for adult patients. The objectives were to explore the primary research activities, and specifically the type of knowledge translation strategies used, the research designs and study settings for such evaluations and the major results thereof as well as identify major research gaps in this area.
Design, methods and approach taken: A scoping review was performed to map the research literature; registered in PROSPERO (#2018 CRD42018100663). Six major databases were searched for the years 2010 to 2019. Eligibility criteria were original articles published in English, in which the knowledge translation of a palliative approach for adult patients was evaluated in non-specialized palliative healthcare settings, and all type of empirical data-based research designs. We excluded non-English, non-empirical articles, non-evaluation of knowledge translations, specialized palliative care settings, and other type of publications.
Results: Most of the183 articles included focused patients with cancer, who are dying, in hospitals and in high income countries, and only 7,1% focused early palliative care. The majority of the articles had core aspects of the research designs unspecified. A variety of strategies for

knowledge translation were utilized, with the most frequently used being conferences, courses and workshops. The evidence base for the implementation strategy was presented in 43,7% of the articles. No knowledge translation strategy was identified as outstanding.

Lessons learned: Detailed reporting of future studies is required. Previous suggestions about the advantage to utilize knowledge from implementation science are confirmed. Specific systematic reviews and meta-syntheses in the field are recommended.

Abstract number: L-58
Abstract type: Poster

Demonstrating the Impact of Palliative Care: A Secondary Analysis of Routinely-collected Person-centred Outcomes Data among Hospice Inpatients

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Background: The use of patient-level outcome measures can support patient-centred care and improve the quality of care provided to patients and their families.

Aims: To estimate prevalence of patients' symptoms; and measure change in symptom scores at first change of Phase of Illness and end of episode of care.

Methods: We used routinely-collected clinical data between Apr.2019–Dec.2020 in secondary data analysis. We estimated prevalence of symptoms as any moderate/severe/overwhelming score using the Integrated Palliative care Outcome Scale (IPOS). We measured mean change of IPOS scores and improvement in outcome (any patient with moderate/severe/overwhelming symptoms to not at all/slightly), at first phase change and end of episode of care.

Results: 1266 patients received 1415 episodes of care. At episode level, median age was 73 years (IQR: 61 – 83), 50% females, and 80% had cancer. Most patients presented in 'deteriorating' (50%) and 'unstable' (37%) Phase of Illness at start of episode of care. By first phase change, mean 'pain' score reduced from 1.96 to 1.62 (25% of 416 patients with moderate/severe/overwhelming pain improved); mean 'breathlessness' score reduced from 1.34 to 1.03, (31% of 263 patients improved); mean 'anxiety' score reduced from 2.04 to 1.80 (15% of 274 patients improved); and mean 'feeling depressed' score reduced from 1.59 to 1.43 (17% of 213 patients improved). By end of episode of care, mean 'pain' score reduced from 1.96 to 1.03 (54% of 309 patients improved); mean 'breathlessness' score reduced from 1.34 to 0.88, (51% of 193 patients improved); mean 'anxiety' score reduced from 2.04 to 1.06 (49% of 182 patients improved); and mean 'feeling depressed' score reduced from 1.59 to 0.80 (59% of 138 patients improved).

Conclusions: This analysis demonstrates how inpatient hospices can systematically use routinely-collected outcomes data to demonstrate the positive impact of the care they provide.

Funding: Yorkshire Cancer Research (L412)

Abstract number: L-59
Abstract type: Poster

Assessing the Impact of Training Using the Serious Illness Conversation Guide – Pediatric Adaptation (SICG-Peds) on Clinician-family Communication

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Background: An essential component of high-quality and patient-centered care for children with life-limiting conditions is eliciting families' values, priorities and goals about their child's future health care. The Serious Illness Conversation Guide – Pediatric Adaptation (SICG-Peds) provides a standardized approach to communication, which has been developed to include patient and caregiver tested language, incorporating best available evidence.

Aims: We aim to assess the impact of SICG-Peds training workshops on clinicians' skills and confidence in leading serious illness conversations with families, and to identify barriers to clinician implementation of these communication techniques in their practices.

Methods: Clinicians participating in SICG-Peds workshops were surveyed about their knowledge, comfort, and attitudes in the management of difficult communication scenarios before and after SICG-Peds workshops (immediately and 6 months). Semi-structured interviews were also conducted with clinicians 6 months after the workshops.

Results: Ninety-four healthcare providers participated in the study. Before the workshop, most participants identified training (54%), mentoring (48%), and a framework for communication (53%) as their most significant learning needs. At six month follow-up, 59% of participants reported conducting serious illness conversations with parents at least four times. The most common barriers to incorporating SICG-Peds into clinical practice were a lack of adequate time and space, lack of experience, and differences in cultural or linguistic backgrounds.

Conclusions: SICG-Peds workshops support pediatric clinicians' skill and confidence in initiating and leading conversations focused on families' values, priorities and goals for their child's health. Future studies exploring the longer-term impacts of serious illness training are needed.

Abstract number: L-60
Abstract type: Poster

An Investigation into the Administration of Haloperidol, Levomepromazine and Midazolam to Inpatients Dying of COVID-19 at a Tertiary Hospital during the Coronavirus Pandemic in the UK

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Background: In April 2020, UK national and local guidelines for symptom control at the end of life were revised to indicate that higher doses of anti-agitation medication (AAM) might be required for patients dying due to COVID-19 .

Aims: To investigate AAM (haloperidol, levomepromazine or midazolam) doses administered to inpatients dying of COVID-19 at a tertiary hospital during the first wave of the pandemic.

Methods: Electronic prescribing records of hospital inpatients who died of COVID-19 between 15*th* March and 15*th* June 2020 were examined (excluding patients dying on intensive care unit). Doses of AAM administered in the last 48 hours of life were recorded anonymously from electronic prescribing records, including administration route, and analysed by descriptive statistics. The School of Pharmacy Ethics committee granted ethical approval.

Results: Included inpatients (n=258), were predominantly male (55%) and White British (70%). In total, 132 inpatients received at least one AAM via any administration route. The majority of inpatients (n=116) received at least one dose of '*as required*' AAM as a subcutaneous

injection. 92% of those inpatients received midazolam (median dose 5mg), 24% received levomepromazine (median dose 6.25mg) and 3% received haloperidol (median dose 2mg). For inpatients receiving at least one AAM via continuous subcutaneous infusion (n=55), 89% received midazolam (median dose 10mg/24 hours), 16% received levomepromazine (median dose 12.5mg/24 hours), and 5% received haloperidol (median dose 2.5mg/24 hours).
Conclusion: Our results indicate that doses of AAMs administered to our inpatients dying of COVID-19 were more in line with 'usual practice' and not as high as anticipated in view of the revised guidance. Our next step is to interpret these results in the context of the dying patients' actual symptom burden.

Abstract number: L-61
Abstract type: Poster

IMPaCT: How to Achieve Integrated Person-centred Care

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Background: Several services may be involved in the care of palliative patients. However, often there is a lack of communication between these services which can lead to fragmentation and duplication of care. The IMPaCT (Integrated Mersey Palliative Care Team) service is a multiprofessional collaboration between hospice, hospital and community palliative care teams which can be accessed by adult patients in Liverpool and South Sefton with a life-limiting condition.
Aim: IMPaCT aims to promote collaborative working in order to provide a streamlined, holistic approach and ensure that the patient is seen by the right professional at the right time.
Design, methods and approach taken: The IMPaCT pilot, covering an area in south Liverpool, launched in January 2020. The service expanded to cover all of Liverpool and South Sefton in October 2020.
Patients, carers and professionals can contact IMPaCT via a telephone advice line. Professionals may also make written referrals. Calls and referrals are dealt with by the cross-organisational and multidisciplinary team, who discuss each case and ensure that the patient is assessed by the professional who can best meet their needs.
A Huddle meeting occurs four days per week, and is attended by hospice, hospital and community teams. It allows new referrals and patients of concern to be discussed. A weekly integrated multidisciplinary team meeting allows more in-depth discussion, for example of cases where there are complex ethical issues.
Results: IMPaCT has received 310 calls since its launch. There have been over 200 Huddle meetings, which have promoted networking and insight into other professional roles and responsibilities. Feedback from patients, carers and professionals has been positive.
Conclusion: IMPaCT demonstrates that integration of palliative care services city-wide is possible. We will conduct a formal evaluation of IMPaCT to assess its effectiveness in improving palliative care in the region.

Abstract number: L-62
Abstract type: Poster

Classifying Specialized Palliative Care – Development of a Typology for Germany

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Background: In Germany, specialized palliative care (SPC) is provided by palliative care units (PCU), palliative care advisory teams in hospital settings and palliative home care teams. Thus, the differentiation between the three care settings can serve as a first level of classification. However, due to profound variations in regulatory structures and financing systems across Germany, services within each setting are heterogeneous and characteristics remain unclear. The existing level of classification is insufficient for a clear description, distinction, and comparison of SPC services, which impedes quality control.
Aim: Development of a comprehensive classification to facilitate the description and differentiation of SPC models in Germany.
Methods: Qualitative study throughout Germany including the development of a literature-based, preliminary list of structural and processual characteristics, 11 semi-structured expert interviews, and 2 focus groups. Verbatim transcripts of the interviews and focus groups were evaluated by content-analytical techniques.
Results: Characteristics of SPC models need to be considered as a whole to allow for differentiation. Thus, services should be described on a polyhierarchical basis, such as a typology, representing relevant heterogeneous characteristics. Several structure characteristics (e.g. size, professional groups, funding), and process characteristics (e.g. quality assurance measures, range of services) were identified as suitable features for an enhanced specification of SPC in Germany. A classification in form of a typology including all relevant characteristics has been developed.
Conclusion: The advanced typology refines the existing level of differentiation within SPC services in Germany and paves the way for an improved understanding and benchmarking of services. In terms of quality development this deeper insight into structure and process characteristics of SPC is necessary not only for Germany but internationally.

Abstract number: L-63
Abstract type: Poster

Palliative Care Professionals as an Important Resource in Multidisciplinary Cancer Meetings: The Experience of a Peripheral Hospital in Portugal

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Background: As oncology knowledge arises, multidisciplinary team meetings represent an important tool for an accurate oncology approach. They usually include different health workers but despite the percentage of palliative patients in oncology, palliative care professionals are not usually integrated in this teams in our country.
Aim: To demonstrate the importance of the integration of palliative care professionals in multidisciplinary cancer team meetings.
Methods: Retrospective and comprehensive study including patients with palliative needs, who were discussed in our multidisciplinary team meeting during 1 year (2019), after the integration of palliative care professionals. Data was obtained from patients' clinical process and analyzed by SPSSv25.
Results: A total of 230 patients were identified as having palliative care needs, 110 women, 120 men, median age of 73 years old. Most frequent tumour location was colorectal, breast and gastric cancer, representing together 52% of total. 72.6% of patients had other comorbidities other than cancer and 76% presented a metastatic disease at the time of the meeting, 55% having multiple locations for metastasis.

Regarding meeting decision: 69% were under oncology treatment and after deterioration 129 patients were candidates to an exclusive palliative care approach, 136 patients were referred or accompanied by a palliative care team and 45 were followed by a community team. 64% died meanwhile, 30% died at home and 17% at a palliative unit, 45% died at the hospital, 20.3% in the emergency department.

Conclusions: This study shows the impact of palliative care needs in oncology and that such care is not mutually exclusive with oncology care. Inclusion of such teams in multidisciplinary meetings is important, as it helps us to identify patients with palliative care needs at an early onset of the disease, giving the opportunity of a right symptom control and to help to coordinate resources to improve end of life quality.

Abstract number: L-64
Abstract type: Poster

Is Proximity to a Radiotherapy Centre Associated with a Decreased Use of Palliative Radiotherapy? A Systematic Review

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Background: Palliative radiotherapy (PRT) has been shown as an effective way of reducing some of the symptoms that arise with advanced incurable cancer. Several studies have now sought to assess what factors contribute to inequalities in PRT utilization among cancer patients, identifying travel distance to a radiotherapy centre as one of the potential barriers.

Aim: To assess whether there is an association between travel distance to a radiotherapy centre and utilisation of PRT in adults with cancer.

Methods: The study is a systematic review with the protocol registered on PROSPERO (CRD42020190772). A systematic literature search was conducted using MEDLINE, EMBASE, CINAHL, and APA-PsycINFO upto 16 February 2021. Quality was assessed using the Newcastle-Ottawa Scale.

Results: A total of 2170 studies were screened resulting in 24 studies that met the inclusion/exclusion criteria. Nine studies focused on the association between living further away from the radiotherapy centre and the use of single-fraction (SF) vs multi-fraction PRT. Of these, 8 reported that those living further away were more likely to receive SF PRT and 1 showed no significant difference by distance. Fifteen studies focused on receipt of PRT vs not receiving PRT. Eleven studies reported that living further away from a radiotherapy centre was associated with being less likely to receive PRT, with 4 studies reporting no difference based on distance. The majority of studies were from North America (16) with 7 from Europe and 1 from Australia.

Table 1. Metrics for GSF assessment on CCU Aug 2020 – Jan 2021.

	Mean percentages
% ward patients assessed for GSF	90%
% GSF Green and Amber offered advance care planning	30%
% GSF identified patients with preferred place of care recorded	60%
% GSF red identified patients with priorities for care communication	60%
% of deaths identified as GSF Amber or Red	60%

Conclusion / Discussion: This systematic review identified that patients with cancer living further from radiotherapy centres were less likely to receive PRT and where they received PRT, they were more likely to receive SF PRT, providing some evidence of inequalities in access to PRT treatment based on distance. It will be important to understand whether these inequalities are a result of referral bias or patients not willing or able to travel longer distances.

Abstract number: L-68
Abstract type: Poster

The Impact of whole Hospital GSF Implementation at the Dudley Group NHS Foundation Trust during COVID

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Background: A third of hospital patients are in their last year of life and almost 50% of people die in hospital. Gold Standards Framework (GSF) is a quality improvement programme enabling coordinated care for people in the last year of life. The Dudley Group NHS Foundation Trust (DGFT) introduced GSF across the whole hospital, enabling ward staff to become more confident in end-of-life care.

Method: The DGFT introduced GSF to the whole hospital from April 2018 . They had several resources already available to support end-of-life care and worked with IT to enable recording of information related to GSF via the electronic patient record system. This enables staff to view patients that have been identified as part of the GSF, including supporting advance care planning, priorities for care and recording preferred place of care.

Results: A yearly audit identified that approximately a third of adult inpatients are in the last year of life in the DGFT, averaging at 33%.
Implementation of GSF demonstrated improvements with regards to an individual plan of care including advance care planning. There were an increased number of deaths during COVID with DGFT seeing an increased number of patients identified using the GSF framework.

Table 1. Percentage of deaths identified as GSF amber and red from electronic patient record.

Month	% of deaths with GSF red/ amber care plan
Sept 2020	57%
Oct 2020	41%
Nov 2020	39%
Dec 2020	49%
Jan 2021	47%

Conclusions: Despite this year's challenges with Covid-19, the whole-hospital data collected by DGFT has offered assurance that GSF has continued to be embedded with improved identification of patients in the last year of life, use of data to drive improvements and a noticeable culture change with many examples of individual plans of care.

Abstract number: L-69
Abstract type: Poster

Exhale to Online - Transitioning a Group Exercise Programme to a Telehealth Model in a Palliative Care Setting

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Aim: Due to the Covid-19 pandemic, specialist palliative care services have had to adapt the delivery of service for patient safety, particularly outpatient group interventions.The physiotherapy department had successfully run an exercise and education programme for patients with advanced lung disease who are severely deconditioned, breathless and unsuitable for inclusion in standard rehabilitation programmes. The aim of this project was to adapt the programme from its original format and transition it to an evidence-based telehealth(TH) programme.

Design: We reviewed evidence-based literature examining successful TH service delivery and liaised with an established TH pulmonary rehabilitation service.

Results: Through our research, we identified the following areas of concern; Technology–Considerations for selecting a videoconferencing platform included user-friendliness and quality of audio-visual functions. Instruction leaflets to assist patients navigate the platform were developed. Security measures such as the ability to provide password protected meetings and data encryption were considered.

Safety-A home visit was completed, including a review of exercise precautions. It was recommended that a second person be present during classes. A risk assessment was completed for those without a second person. Classes were facilitated by two physiotherapists; one leading the class while the other monitored patients for adverse events.

This programme has been successfully running for 3 months with no adverse events.

Conclusion/Lessons learned: This project has given us insight into the benefits of having an online platform. Initial concerns regarding patients' ability to master technology were eased and only minimal troubleshooting was required. Future research should investigate whether it is sustainable over a longer period without affecting quality of care. Existing research was limited and this project has provided a platform for which guidelines may be developed.

Abstract number: L-70
Abstract type: Poster

Telemedical Answers to Neurological Inquiries in Realtime - "TANNE"Comprehensive Support for Neurological Patients in an Outpatient Palliative Care Setting

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Background: The project "Telemedical Answers to Neurological Inquiries in Realtime — TANNE", funded by the Innovation Fund of the Federal Joint Committee (G-BA), offers comprehensive support for patients with neurological diseases or symptoms who are cared for in specialized outpatient palliative care teams or in hospices. A video system connects the telemedicine expert center for neuropalliative care with the teams/hospices. Additionally the quality of care is to be increased through supplementary structural work (creation of SOPs, training courses, advanced training events) through the expert center.

Aim: The project intends to introduce telemedicine for neurological consults for palliative patients into standard care.

Methods: Due to a very heterogeneous patient population expected and the complexity of the care model, a multidimensional evaluation design with mixed methods was chosen. A prospective, randomized, two-arm intervention study with a delayed-start design will be conducted to demonstrate the medical effectiveness of the care concept. The concept of care is evaluated at the macro level in terms of outcome and cost-effectiveness parameters and at the micro level in terms of implementation and acceptance. The third level of evaluation highlights the social, legal and ethical challenges.

Over a study period of 24 month, starting in April 2021 data will be obtained on 225 patients cared by specialized palliative care outpatient teams and in hospices.

Results: Experiences from the conception phase and first project phase will be presented.

Conclusion / Discussion: The new model of care is a resource-saving addition to the existing specialized outpatient palliative care, which can easily be transferred to other disciplines.

Abstract number: L-71
Abstract type: Poster

Status of Palliative Day-care Clinics and Day Hospices in Germany: A Mixed Methods Study

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Background: In contrast to countries such as Great Britain, Ireland and the USA, palliative day-care clinics and day hospices in Germany are still in their early days; the establishment and development of these facilities has been unsystematic. Little is known about what services the respective facilities cover and how they are financed and structured.

Aims: This study aims at identifying and systematically analysing the characteristics of palliative day-care clinics and day hospices in Germany as a part of the multi-perspective project ABPATITE (2020-22).

Methods: To capture facility-related criteria, data were collected in exploratory, qualitative interviews with facility managers (06-07/2020) and via a standardised quantitative questionnaire (08-10/2020) sent to all facilities identified nationwide. Interview data were analysed according to the principles of content analysis; quantitative data were analysed using descriptive statistics.

Results: From qualitative interviews with managers of palliative day-care clinics (n=3) and day hospices (n=4), we identified five core concepts regarding facility-related criteria: 1) differences of facility types, 2) intended outcomes, 3) offered services, 4) patient allocation criteria and 5) funding modalities. Palliative day-care clinics and day hospices intend enabling (at least partially) mobile patients to remain in their own home by relieving burden on family caregivers. Of the 22 day hospices and 6 day-care clinics that participated in the survey (response rate: 84.8%), all facilities receive donations; 75% of the facilities claim costs from statutory health insurances.

Conclusions: Study results disclose the specifics of day-care facilities and illustrate the various ways in which these facilities are operating and structured. Further research is needed on how to best integrate hospice and palliative day-care institutions into the German healthcare landscape.

Funding: Innovation Fund of the German Federal Joint Committee

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Abstract number: L-72
Abstract type: Poster

Early Palliative Supportive Care within the Lung Cancer Committee (LCC): Descriptive Study of the Patient's Characteristics after One Year Experience in a Tertiary Hospital

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Background: Many studies have shown benefits of early Palliative Care(PC)in advanced lung cancer patients. There's increasing evidence about better symptom control and survival. A PC physician joined the multidisciplinary LCC last year. Despite the SARS-CoV2 pandemic,472 cases were presented to the LCC in 2020. 470 cases were presented in 2018, so his activity remains stable.

Aims: To describe clinical profile of the patients presented to the LCC and early referred to PC. To compare patient's survival when referred from ambulatory setting or when they are admitted in hospital.

Methods: Descriptive study.DATA:Age, Gender, Comorbilities, Cancer Histology Tobacco exposure, TNM, Oncology Therapy, Survival time, Barthel, Charlson, Time to first PC consultation. ANALYSIS:T test to compare means of continuous variables and Chi-squared to compare proportions of categorical variables. Kaplan-Meier curve for survival analysis.

Results: 41patients of 472(9%) were referred to PC. Males(75%),Median Age 72,87 years old(DS 11,95) no age differences by gender. Current Smokers 25%,Former smokers 65%.Hypertension 70%,Diabetes 45%,Dyslipemia 60%,Heart Failure45%, Renal impairment 35%. Barthel:mean 63,6(DS:22,7) Charlson:mean 6,5(DS2,35)

Cancer Histology: Squamous55%, Adenocarcinome35%, Small Cell 7,5%,Other Neuroendocrine2,5%,

Disease Stage: StageIV 65%, StageIII 55%,

Cancer therapy: Chemotherapy 44%,Radiotherapy 56%, Immunotherapy 30%.PC exclusive follow-up:24,4%, PC and shared follow-up:75,6%.

Setting: Refered to Ambulatory PC: 44%, Refered to PC when admitted in an hospital ward: 56%.

Time from LCC to PC visit: Ambulatory setting: mean 27,7 days, median 14. Admitted hospital ward: mean 63,14 days(p=0,036),

Survival: Ambulatory: mean 142,12 days (DS 90,9), Admitted Hospital ward 59,68 days (DS 59,1)p=0,002.

Conclusion: Patients referred from LCC to Ambulatory PC showed an early intervention and better survival profile. Collaboration between LCC and the PC team can improve the early PC support.

Abstract number: L-73
Abstract type: Poster

The Value of Investment in Nursing Leadership to Build Research Capability and Capacity in Hospices and Deliver High Quality Research within the Multidisciplinary Team

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Goal of the work: The integration of clinical care, education and research is key for hospices to deliver high-quality palliative care. Multiple challenges face hospices including research governance processes as independent businesses, limited research funding and skills, and competing clinical priorities. In 2019 a Florence Nightingale research scholarship was awarded to develop research at St Barnabas Hospices. This aimed to increase research capacity and capability to host and lead palliative care research studies by building a research strategy, robust research governance processes, and research skills for nursing staff within the multidisciplinary team.

Approach taken: A survey of hospice staff to identify research engagement and skills, a literature review to explore the experiences of other hospices and a Research Workshop to share expertise in palliative care research and identify key research priorities with stakeholders from nursing, therapies and medicine, and the executive board, Descriptive data analysis and collation of priorities

Results: 18 staff completed the survey. 80% wanted to increase research activity. This involved establishing a Research Interest Group to develop the research strategy and governance processes, and a monthly journal club to promote evidence-based practice. The Research Workshop identified priorities to link with clinical research networks, collaborative working with healthcare partners and universities. The research strategy detailed research priorities and goals, and investment in research lead and research nurse post. Evaluation at 1-year demonstrates the Hospice has become research active recruiting to national research studies, appointed a research lead and developed formal links with research networks and healthcare partners.

Lessons Learned: The scholarship emphasises the value of investment in nursing leadership to deliver high quality research within the multidisciplinary team.

Abstract number: L-75
Abstract type: Poster

Talking about Death and Dying in the UK: Is it Really a Taboo?

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Background: Understanding public attitudes to death and dying can help inform how we plan and deliver future end of life care. Although UK surveys indicate approximately 70% of people are comfortable talking about death, it is widely referenced as 'taboo' and an active public information campaign encourages us to 'talk about it'.

Aim: To explore the UK public's thoughts about 'talking about' death and dying

Method: Deliberative discussion groups and interviews with a range of public participants. Group members were provided with information resources prior to each meeting as a spur to thought and differing perspectives. Thematic analysis was undertaken.

Results: Forty-one people took part in seven discussion groups and five individual interviews. Participants recognised the idea that death talk was taboo and also that it was a good thing to talk about. However, the reasons were not often clearly articulated and there were few references to initiatives such as Dying Matters or Death Cafes. A sense of death as a core, essential part of life was evident. A strong motivation to talk was to alleviate the burden of decision making and uncertainty for others before and after the individual's death. Participants were also aware that some people found this a difficult topic and were cautious about causing discomfort. Friends and, especially, family were considered to be natural confidantes, rather than health professionals. Such talk usually required a trigger, such as a family death or illness. Funerals and wills were often referenced as key issues, but there was little focus on wishes for end of life care which were considered uncertain and difficult to anticipate or control.

Discussion: Participants were drawn to the research because they found the topic of death interesting, albeit challenging. The idea that discussion of death and dying should be normalised and that 'it's good to talk' was present, but not anchored in the policy discourse of 'the good death'.

Abstract number: L-76
Abstract type: Poster

Golden Years: Improving End of Life Care in Retirement Villages (RVs) with Gold Standards Framework (GSF) RV Programme - Findings from the first GSF Accredited RVs and Reflections in the COVID Crisis

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Context: Retirement Villages (RV) are an increasingly popular choice for the ageing population, with the reassurance of 24-hour on-site staff, communal facilities, and optional high quality personal care support. For many this will be their last move; villages must ensure they offer quality end of life support.

Enabling RV staff to support residents to live well and die well is valuable - more so during COVID. Yet very little specific training is tailored to RVs. Gold Standards Framework (GSF) is a quality improvement programme for generalist frontline staff enabling proactive, person-centred care, with a specific Retirement Village (RV) programme.

Aim: To assess the impact GSF in ExtraCare RVs and reflect on sustaining this during the pandemic.

Method: The GSF RV programme enables staff in early recognition of decline, needs-based coding, offering advance care planning (ACP) discussions to all, improved collaboration with primary care teams, reducing crises and avoidable hospitalisation.

Over 3 years, ExtraCare introduced the GSF RV Programme, Golden Years, to all its 19 RVs. Comparative qualitative and quantitative evaluations later led to GSF Accreditation.

Results: We present a summary of findings of our GSF trained and accredited RVs, the impact to ExtraCare, personal experiences of staff and residents, and reflection of how this helped during the COVID crisis.

Findings from GSF accreditation assessments and visits indicate high levels of GSF adoption with improved EOLC awareness , openness and culture change, earlier identification, more ACP discussions ,staff confidence and competence , collaboration with Primary care, reduced hospital deaths and crises.

Conclusion: This highlights the unique emerging context of RVs in which to raise awareness of improving end-of-life care and, despite being severely tested during the peak of COVID, the benefits of focussed GSF training in providing 'a gold standard of care for the golden years'.

Abstract number: L-77
Abstract type: Poster

Proposal of Core Criteria and Tools for the Italian Palliative Care Network

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Background: Social and health changes in high- and middle-income countries will increase the need for palliative care (PC) in the population; PC networks have to rely on internationally validated criteria and tools that allow to object to the multidimensional evaluation of the care teams, as well as to make the treatment paths homogeneous according to the complexity of needs. The evolution of the PC discipline also requires monitoring the quality of the services through the outcome measures of the interventions provided to patients and their families.

Aim: To identify criteria and tools, based on scientific evidence and validated in Italian, that represent the core of tools for evaluating patients in PC networks.

Methods: Within the Italian Society of Palliative Care, Tuscany section, has been established a Multidisciplinary Group (MG), consisting of doctors and nurses related to the PC networks of the Region. The MG worked through online meetings. Instruments validated in the literature and in accordance with the National Consensus Project for Quality Palliative Care, validated in Italian, have been considered to:

early identification of patients with PC needs, in the different care settings;
diagnose the complexity of PC needs;
perform multidimensional evaluation;
estimate the prognosis of survival.

Results: The literature analysis identified the following tools, which meet the proposed objectives and methods:

Supportive and Palliative Care Indicators Tool (SPICT TM)
Necesidades Palliativas (NECPAL CCOMS-ICO© tool)
Instrumento Diagnòstico de la Complejidad en Cuidados Paliativos (IDC-Pal)
Core di strumenti Outcome Assessment and Complexity Collaborative Suite of Measures (OACC)
Palliative Prognostic Index (PPI)
Palliative Prognostic Score (Pap Score).

Conclusions: The aim of the MG is the gradual introduction of the aforementioned tools into italian PC networks and the involvement of the scientific society for a contribution to the training plan.

M Posters Primary and Integrated Care

Abstract number: M-01
Abstract type: Poster

The Character of Early Palliative Care Interventions on Adult Clinical Oncology: Results of a Systematic Review

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Background: Implementing palliative care early in clinical care is an important and promising approach. However, there is ambiguity about the timing and nature of these palliative care interventions.

Aims: We analyzed the program variables of so called 'early palliative care' (EPC) interventions for adult patients in clinical oncology care to show congruent as well as diverging elements embedded in scientific studies that aim to evaluate the effectiveness of EPC.

Methods: We conducted a systematic review searching Medline, Cinahl, Central and PAPAS database up to May 2020. Inclusion criteria were: a) adult patients, b) clinical oncology setting, c) self-labelling as 'early palliative care', d) (non) randomised-controlled trials (RCTs) or cohort studies (CS). We analyzed the interventions based on the domains of the Template of Intervention Description and Replication. Prospero ID: 2344324.

Results: We screened 2222 articles and 28 studies (22 RCTs, 6 CS) met the eligibility criteria for inclusion. Patients with lung (n=11), pancreas (n=7) and unspecified advanced cancer (n=5) were the most common target groups. A majority of studies focused on a timeframe of 8 weeks after diagnosis for initiating EPC. Interventions comprised a wide range such as symptom management, psychosocial care, counseling, case management and care planning. There was a lack of reporting in particular for the process of the intervention and control groups as well as the theoretical foundation of the interventions.

Discussion: Our analysis suggests that there is great diversity in EPC interventions. The explication of the processes, theories underlying and needed expertise for EPC is needed from a research perspective to be able to develop and evaluate these interventions in a reliable and valid way. In addition, such clarification seems also important from a clinical perspective for health professionals as well as patients offered EPC.

This research received no funding.

Abstract number: M-02
Abstract type: Poster

Improved Quality and Reduced Costs of End-of-Life Care if Older People with Dementia Receive Palliative Care: A Nationwide Propensity-matched Decedent Cohort Study

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Background: While palliative home care is advocated for people with dementia, evidence of its effectiveness is lacking, potentially due to the ethical, legal and practical challenges of conducting traditional experimental studies in this context. The best possible alternative is to emulate a target trial using a matched cohort study design with a high-quality matching on the propensity of receiving an intervention.

Aim: We aimed to evaluate the effects of palliative home care on quality and costs of end-of-life care for older people with dementia.

Methods: We conducted a decedent cohort study using linked eight nationwide administrative databases and propensity score matching. Participants included all home-dwelling older people who died with dementia between 2010 and 2015 in Belgium (N=23,670). Exposure is the receipt of palliative home care for the first time between 360 and 15 days before death.

Results: 5,637 (23.8%) received palliative home care support in the last two years of life, of whom 2,918 received it for the first time between 360 and 15 days before death. 2,839 people who received support were matched to 2,839 people who received usual care. After matching, those using palliative home care support, in the last 14 days of life, had lower risk of hospital admission (17.5% vs 50.5%; relative risk [RR]=0.21, 95%CI=0.2-0.2), undergoing diagnostic testing (17.0% vs 53.6%; RR=0.20, 95%CI=0.2-0.2) and receiving inappropriate medications; and were more likely to die at home (75.7% vs 32.6%; RR=6.45, 95%CI=5.8-7.3) and to have primary care professional contacts (mean 11.7 [95%CI=11.5-11.9] vs mean 5.2 [95%CI=5.0-5.4]), compared with those who did not. Further, they had lower mean total costs of care in the last 30 days of life (incremental cost:−€2129 [$p<0.001$]).

Conclusions: Palliative home care use by home-dwelling older people with dementia is associated with improved quality and reduced costs of end-of-life care. Access remains low and should be increased.

Abstract number: M-04
Abstract type: Poster

Palliative Care Integration in a Cohort of Dialysis Patients

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Background: Maintenance dialysis conveys a significant mortality burden indicating a need for appropriate end-of-life planning and care.

Aim: To investigate the demographic and clinical characteristics of deceased dialysis patients and the extent of palliative care integration before death.

Methods: Retrospective cohort study of adult patients cared for by Eastern Health Integrated Renal Service who died between 1/1/2016 and 31/12/2019.

Results: Over three years, 113 patients died: mean age 74 years, modified Charlson Comorbidity Index 9.8, 28% female. All were on long term dialysis (mean duration 64 months), 89% haemodialysis, 11% peritoneal dialysis.

Place of death was known for 105 patients: 40% in acute inpatient ward (91% on the renal ward), 10% intensive care, 15% hospice, 13% residential care facility and 10% at home. Preferred place of death was known in 39% and was met in 66% of those.

Of 101 records specifying cause of death (89%), forty deaths were renal-related (35%). Sixty-one had another cause: sepsis (19%), cardiac (11%), stroke (5%), ischaemic bowel (4%), malignancy (3%) and gastrointestinal bleeding (2%). Dialysis was ceased at least four days prior to death in 55 (49%) [median 8 days, IQR 6-11]. A summary of symptom prevalence in the last 24 hours of life is shown in Table 1.

A goal-of-care discussion in the preceding twelve months was documented in 75 (66%), mostly undertaken in renal outpatient clinics (53%), and advanced care directives were documented in 28 instances (25%).

Palliative care was involved in 62 patients: 57% inpatient, 13% community service, 30% both. Median time between palliative care involvement and death was seven days [IQR 3-22], which reduced to 3.5 days [IQR 2-9.5] for inpatients.

Conclusions: Despite most patients dying in hospital with high comorbidity and symptom burden, these results suggest limited and late palliative care involvement. Our results indicate an opportunity to integrate palliative care services earlier.

Table 1. Symptoms in final 24 hours of life in dialysis patients.

Symptom	Symptom present n (%)	Symptom absent n (%)	Symptom not assessed/ documented n (%)
Agitation	30 (27%)	35 (31%)	20 (18%)
Drowsiness	63 (56%)	7 (6%)	13 (12%)
Dyspnoea	34 (30%)	32 (28%)	16 (14%)
Noisy Breathing	16 (14%)	38 (34%)	30 (27%)
Pain	30 (27%)	43 (38%)	11 (10%)
Nausea	10 (9%)	48 (42%)	24 (21%)
Constipation	8 (7%)	42 (37%)	34 (30%)
Anxiety	6 (5%)	17 (15%)	62 (55%)
Spiritual Distress	7 (6%)	15 (13%)	62 (55%)

Abstract number: M-06
Abstract type: Poster

Professionals' Experiences with Implementing Integrated Palliative Care for Patients with COPD: "This Really Adds to the Quality of Care We Provide!"

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Background/ aims: In a hybrid type 2 effectiveness-implementation study, healthcare professionals (HCPs) of four hospital regions were trained in identification of palliative patients with COPD, multidimensional assessment, advance care planning (ACP) and care coordination. Subsequently, HCPs implemented these intervention elements in their region. To facilitate future implementation efforts, we examined HCPs' intervention experiences and identified barriers and facilitators.

Methods: Semi-structured interviews were held with pulmonologists, COPD-nurses, general practitioners (GPs) and palliative care nurses. Data were inductively coded and analysed using content analysis. Next, barriers and facilitators were mapped to the domains of the Consolidated Framework for Implementation Research.

Results: Six HCPs per hospital region (total n=24) participated; Interview duration varied (20 to 85 minutes). Most participants highly valued the intervention, and mentioned that ACP discussions provided patients with peace of mind and clarity, improved the HCP-patient relationship and increased job satisfaction. Collaboration between the hospital and GPs was inadequate in all regions, as judged by both primary care and hospital

HCPs. The (satisfaction with the) extent of involvement of palliative care consultants varied. Key barriers identified were related to the inner setting (e.g. insufficient time, low priority due to COVID) and process (e.g. difficulty of engaging stakeholders). Key facilitators were related to the process (e.g. consistently planning of ACP discussions, regular meetings with a small project group) and inner setting (e.g. recognition that ACP is valuable).
Conclusions: HCPs express that palliative care for patients with COPD is valuable because of its positive impacts on patients and HCPs. For successful implementation, we recommend to use a process-oriented approach. Further, more work is needed to improve collaboration between hospital and primary care HCPs.

Abstract number: M-07
Abstract type: Poster

Is Social Support, Health Status and Activities of Daily Living Associated with Burden of Symptoms in a Chronic Lung Disease Population? A Cross-sectional Study from Cape Town

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Background: The majority of deaths globally are attributable to non-communicable disease and four-fifths of these deaths are in low and middle-income countries. COPD is currently the fourth leading cause of death globally and is predicted to be the third leading cause of death by 2030. We aimed to determine the prevalence and burden of symptoms, and to assess the associating factors among patients with chronic lung disease.
Methods: We conducted a cross-sectional survey at eight primary care sites in Western Cape. Socio-demographic data (age, gender, smoking status, number of missed doses) and clinical data (FEV1 and KPS) were collected. Patients also completed the Memorial Symptom Assessment Scale (MSAS), the Medical Outcomes Study (MOS), Social Support Survey, the London Chest Activity of Daily Living Questionnaire and the COPD Assessment Test (CAT). We conducted ordered logistic regression analysis to assess factors associated with the burden of symptoms. The dependent outcomes were MSAS subscales: global distress index, physical symptom distress and psychological symptom distress. We constructed three ordinal logistic regression models for each of the three MSAS subscales. Covariates were demographic and clinical variables.
Results: We recruited n=387 patients. The mean age was 59.5 years. Just over half were females (n=205, 53.0%). In a multivariate analysis global symptom distress, psychological and physical symptom distress were all positively associated with CAT scores; $p<0.001$, difficulty to perform activities of daily living; $p<0.001$ and low social support; $p<0.001$). Old age was associated with lower global symptom distress, psychological and physical distress status. Participants, who missed 1 or more doses were associated with increasing levels of global and physical symptom distress.
Conclusion: The high burden of physical and psychological symptoms provides strong evidence of the need for integrating palliative care in primary care settings.

Abstract number: M-09
Abstract type: Poster

How Many EMS Calls Are Dispatched to End-of-Life Patients? Analysis of National Registers

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Background: Emergency medical services (EMS) are frequently responding to calls involving patients in advanced stages of incurable diseases. Quantification of the problem is lacking in the litterature, though. An estimate was previously only available for Germany – 3% of the EMS calls being dispatched to end-of-life cancer patients.
Aims: We analysed incidence of EMS transports of end-of-life patients in the Czech Republic in order to quantify the extent of the problem.
Methods: This is a retrospective analysis of all deaths that occured in 2018 in the Czech republic. The data originated from three national registers administered by The Institute of Health Information and Statistics. We were asking two questions:

1. "How many cancer patients are attended to by EMS in the last 3 and 30 days of their life?"
2. "How many deaths, considered as predictable, are preceded in the period of 3 and 30 days before death by an EMS response?"

Results:

1. Of the total number of deaths from cancer diagnosis in the country in 2018, EMS intervened in the last 30 days of their lives in 5583 patients (20.2%). In 3,784 patients, representing 13.7% of all cancer deaths, EMS response was dispatched in the last 3 days of life.
2. From a total of 12,417 deaths in Prague in 2018, 7,326 could be seen as predictable based on diagnosis and hospitalization history. More than a half of these patients died in acute-care settings (n=3,766). 2,317 of these patients were transported to their last hospitalization by EMS. This accounted for 1,9 % of all Prague EMS events (n=121,887 per year). One third of these end-of-life patients were cancer patients.

Conclusion: 244 cancer patients transported during the last 3 days of their lives represents 0.3% of all emergency calls of the Prague EMS.
Funding: This study was supported by a grant from the foundation "Nadace moudré pomoci".

Abstract number: M-11
Abstract type: Poster

The Association of Primary Care Services with Emergency Visits and Hospital Admissions at the End-of-Life in People with Cancer: A Retrospective Cohort Study

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Background: Inappropriate acute care interventions at the end of life can reduce patients' quality of life and satisfaction. We aimed to examine three indicators of potentially inappropriate acute care use for end-of-life cancer care and the associations with primary and community care use.
Methods: Retrospective cohort study using Discover, a linked administrative and clinical dataset from primary care, community and hospital records in London. People with cancer who died between 2016-2019

were included. We examined factors associated with three indicators of potentially inappropriate acute care use: >=3 hospital admissions during the last 90 days, >=1 hospital admissions in the last 30 days and >=1 emergency department (ED) visits in the last 2 weeks of life.
Results: Of 3581 people, 490 (13.7%) had >=3 hospital admissions in last 90 days, 1640 (45.8%) had >=1 admission in the last 30 days, 1042 (28.6%) had >=1 ED visits in the last 2 weeks of life, and 1069 (29.9%) had more than one of these three indicators. Having more contacts with the primary care practice (>11 vs <3) was associated with a higher likelihood of >=3 hospital admissions in the last 90 days (RR 1.63 95% CI 1.33 to 1.99) and ED visits in the last two weeks of life (RR 1.27 95% CI 1.10 to 1.47). Conversely, contacts with community nurses (>=13 vs <4 contacts) were associated with fewer admissions in the last 30 days (RR 0.88, 95% CI 0.79-0.97) and ED visits in the last 2 weeks of life (RR 0.79, 95% CI 0.68-0.92). People living in care homes were less likely to had >=3 hospital admissions in last 90 days (RR 0.43 95% CI 0.24 to 0.78), >=1 admission in the last 30 days (RR 0.54 95% CI 0.41 to 0.72) and ED visits in the last 2 weeks of life (RR 0.71 95% CI 0.51 to 0.99).
Conclusions: Hospital admissions and ED visits in the last month of life are frequent. Expanding community nursing and care homes services could play a role reducing inappropriate acute care interventions.

Abstract number: M-14
Abstract type: Poster

Attitudes of Primary Care Providers on Early Palliative Care, in New Community Settings of Attica, Greece: A Qualitative Analysis

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Background: Early provision of palliative care globally can be achieved by primary health professionals. In Greece, a primary care reformation is currently under development; novel community units have been introduced, with the family physician working for the first time with an interdisciplinary team.
Aims: To explore the attitudes of such providers, on early palliative care in Attica. A clear understanding of primary care workforce attitudes would facilitate the National primary care strategic development.
Methods: Qualitative research design, with 3 focused-groups of 23 primary health care providers, including family physicians, nurses, health visitors, administrative assistants and sociologists. All were members of the Hellenic Association of Research and Education in Primary Care. Semi-structured question guides were used. Experiences, practices, needs and barriers were evaluated. Responses were audio recorded, transcribed, grouped under various themes, listed out and analyzed, through thematic analysis.
Results/Discussion: Three major themes were identified and all teams were able to:

1) Identify patient and family populations with palliative care unmet needs, early at diagnosis.
2) Respond to those needs by the holistic model of care and integrate strategies of early palliative care, working as a team.
3) Recognize barriers to the best-possible approach:
    a) lack of education on severe pain and grief management,
    b) lack of collaboration with experts, and
    c) instability of governemental decisions.

Conclusion: Teams of primary care providers in Attica, could integrate early palliative care. Issues to be addressed include further education on pain and grief management, collaboration with palliative care experts and stability.

Abstract number: M-16
Abstract type: Poster

Analysis of Emergency Calls to Palliative Care Patients in Prague, Czech Republic

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Background: Emergency medical services (EMS) are frequently responding to calls involving patients in advanced stages of incurable diseases. The Emergency Medical Dispatch Centre of the Prague EMS (Czech Republic) has a classification algorithm used for all emergency calls. In 2019 a new classification was introduced and one part is described as: "Deterioration of health conditions – Deterioration of vital signs in a patient in palliative care, but without failure of vital signs".
Aims: This abstract presents the incidence of emergency calls of Prague EMS to a patient with identified palliative care needs.
Methods: This is a retrospective analysis of emergency calls of the internal dispatcher software. All calls with classification "Deterioration of health conditions" in palliative care patients in the year 2020 were included. We were looking for frequency of calls within time of a day, day of a week and month of a year. One sample T-Test was used to find the difference between the variables.
Results: There were 115081 emergency events in total (for a population of approx. 1.3 million inhabitants), of which 2920 met the inclusion criteria (2.53 %), which means approx. 8 emergency calls to a patient with identified palliative care status a day during the year 2020. Significant differences were found in time of day ($p<0.01$) and day of a week ($p=0.01$), no difference was found in months of a year. The calls start to rise from 8am with peak at 10am and begin to decline at 7pm. Less calls are incoming during the weekend.
Conclusion: Those data might help understand better the situation and motivations of callers in end-of-life medical emergencies. Also, these preliminary findings suggest review of some empirical beliefs: for example presumption that EMS is frequently called at out-of-hours period.
Funding: This study was supported by a grant from the foundation "Nadace moudré pomoci".

Abstract number: M-17
Abstract type: Poster

Using the surprise question to assess palliative care needs in ambulatory population with heart failure: a prospective cohort study

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Background: The first step toward increasing access to palliative care (PC) for people living with heart failure (HF) is to identify which patients would benefit from it. The 'Surprise Question' (SQ) was developed to identify patients who might benefit from PC due to a limited life expectancy. Its performance among ambulatory HF population was unknown.
Aims:

1) assess the performance of the SQ predicting 1-year mortality among HF patients,

2) assess which characteristics of HF patients are associated with the SQ when used by a cardiologist, and
3) evaluate the relation between 1-year mortality and the variables associated with the SQ.

Methods: This prospective cohort included 174 ambulatory HF patients recruited from two HF clinics between 2017 and 2018. For our first aim, we calculated the sensitivity, specificity, and the positive and negative likelihood ratios (LR) of the SQ. For our second aim, we conducted a multivariariable logistic regression including explanatory variables that reached significance in the univariate analysis. Using a backward stepwise approach, we obtained the model that best explained the data. For our third aim, we performed a multivariable logistic regression including as covariates those variables included in the final model of the second aim and mortality as the outcome.
Results: The sensitivity was 85% and the specificity 57%. The odds of a positive SQ increased with patient age $\geqslant$70 years, being NYHA III or IV, having obstructive sleep apnea, and hypothyroidism, and decreased with higher scores of the SF-12 physical summary. We found a lack of association for those same variables when we analyzed 1-year mortality.
Conclusion: Based on the limited performance of the SQ predicting 1-year mortality and the fact that it is a tool based solely on life expectancy and does not comprehensively assess the potential needs of the patient or family, it should not be used as a PC screening tool of first choice in this population.

Abstract number: M-18
Abstract type: Poster

Community End-of-Life Care during the COVID-19 Pandemic: Initial Findings of a UK Primary Care Survey

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Background: Thousands of people in the UK have required end-of-life care in the community during the COVID-19 pandemic. Primary healthcare teams (general practice and community nursing services) have provided the majority of this care, alongside specialist colleagues. There is a need to learn from this experience in order to inform future service delivery and planning.
Aim: To understand the views of general practitioners and community nurses providing end-of-life care during the first wave of the COVID-19 pandemic.
Methods: A web-based, UK-wide questionnaire survey circulated via professional general practice and community nursing networks during September and October 2020.
Responses were analysed using descriptive statistics and an inductive thematic analysis.
Results: Valid responses were received from 559 individuals (387 community nurses, 156 General Practitioners (GPs) and 16 unspecified role), from all regions of the UK. The majority reported increased involvement in providing community end-of-life care. Contrasting and potentially conflicting roles emerged between GPs and community nurses. There was increased use of remote consultations, particularly by GPs. Community nurses took greater responsibility in most aspects of end-of-life care practice, particularly face-to-face care, but reported feeling isolated. For some GPs and community nurses, there has been considerable emotional distress.
Conclusion: Primary healthcare services are playing a critical role in meeting increased need for end-of-life care in the community during the COVID-19 pandemic. They have adapted rapidly, but the significant emotional impact, especially for community nurses, needs addressing alongside rebuilding trusting and supportive team dynamics.

Abstract number: M-19
Abstract type: Poster

An Online International Comparison of Palliative Care Identification in Primary Care Using the Surprise Question

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Background: The Surprise Question [SQ] ("Would I be surprised if this patient died within 12 months?") identifies patients in the last year of life. The accuracy of the tool is inconsistent however; it is unclear if "surprised" means the same for each clinician, or whether their responses are internally consistent.
Aims: To determine the consistency with which the SQ is used in primary care.
Methods: An online study of participants located in Belgium, Germany, Italy, the Netherlands, Switzerland, or the UK. Eligible participants were registered General Practitioners (GPs). Participants completed 20 hypothetical patient vignettes. Outcomes: continuous estimate of probability of death within 12 months (0% [certain survival]-100% [certain death]); SQ [Yes/No]. A threshold and an inconsistency range were calculated. Threshold: probability estimate above which answers to the SQ were consistently yes or no. Inconsistency: range of probability estimates where respondents vacillated between responses. Univariable and multivariable linear regression were completed. (NCT03697213 registered prospectively 29/03/2019).
Results: Of 307 GPs who started study, 250 completed 15 or more vignettes. Participants had a consistency threshold of 49.8% (SD 22.7) and an inconsistency range of 17% (SD 22.4). Italy had a significantly higher threshold than other countries (p=0.002). 113 (45.4%) participants were completely consistent in their estimates. There was a difference in threshold levels depending on age of clinician, for every yearly increase in age, participants had a higher threshold, but no statistical difference in participants with specialist palliative care postgraduate training.
Conclusion: There is variation between clinicians regarding the use of the SQ. Over half of GPs were not internally consistent in their responses to the SQ. A limitation may be the hypothetical nature of the assessment: future research is warranted.
Funding: Marie Curie Cancer Care (MCCC-FPO-16-U).

Abstract number: M-20
Abstract type: Poster

Cultural Adaptation of the Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem) for the Swiss Context: A Focus-group Interview Study with Relatives, District Nurses, and Acute Care Nurses

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Background: People with advanced dementia (PwD) are affected by symptoms and needs which are challenging for nurses and relatives to elicit. The Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem), developed in England and translated into German, is a comprehensive, person-centred measure to aid caregivers identify symptoms and needs. Cultural adaptation to the Swiss primary care context is needed before use.
Aims: To culturally adapt the IPOS-Dem for a Swiss context, assess clinical utility, and inform implementation for future use.
Methods: Semi-structured, online focus-group interviews with district nurses (DNs), acute care nurses (ACNs), and relatives. Discussions focused on comprehension and clinical utility (value, scope, content) of the IPOS-Dem when caring for a PwD. Focus groups were recorded and transcribed verbatim. Thematic content analysis using an inductive approach was performed.
Results: Three focus-groups with DNs (n=6), ACNs (n=5), and relatives (n=4). IPOS-Dem was reported as a valuable tool for use in the Swiss primary care context, as it takes the view of the PwD in a process guided environment. 1) DNs felt it provided an overview of the current situation for targeted interventions but recommended "physical contact" be added. 2) Relatives recommended use earlier in the dementia course to help preparedness for future care planning and recommended its use to facilitate focused communication with health care professionals. 3) ACNs determined IPOS-Dem would be of value in interdisciplinary discussions but needed to know the PwD well to complete to support discharge planning.
Conclusion / Discussion: IPOS-Dem was recognised as a valuable addition to the assessments already in use by all groups. IPOS-Dem was reported to be readily adapted by nurses and relatives, with mutual benefit by maintaining communication with key players throughout the advanced dementia trajectory.
Funding: Study supported by Zurich University of Applied Sciences

Abstract number: M-21
Abstract type: Poster

Electronic Palliative Care Coordination Systems (EPaCCS): What Works for whom and in What Circumstances? A Realist Evaluation

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Background: EPaCCS aim to provide a shared record for Health Care Professionals (HCPs), summarising information about patients' preferences and plans for care. They are in use across the UK, although empirical evidence into their effectiveness is poor.
Aims:

1. Describe the socio-demographic characteristics of patients who die with an EPaCCS record and their cause and place of death, and compare these with patients who die without an EPaCCS record.
2. Explore the impact of an EPaCCS on the experience of receiving end of life care for patients and carers, and understand HCPs' views and experiences of using an EPaCCS.

Methods: This is a mixed-methods realist evaluation of the impact of an EPaCCS on end of life care, as provided by one Clinical Commissioning Group (CCG) in England. The study was conducted in five phases:

(1) development of the initial programme theory;
(2) focus group with CCG stakeholder board;
(3) individual interviews with twenty-one HCPs, four patients, one current, and seven bereaved, carers;
(4) retrospective cohort study of routinely collected data on EPaCCS usage and
(5) data analysis and synthesis of study findings.

Results: Uptake and engagement with the EPaCCS was variable and dependent on engaged leadership. Only 18% of the study sample died with an EPaCCS record and people who died of cancer were more likely to have an EPaCCS record (27%) than those who died of a non-cancer cause (15%). The EPaCCS concept was valued by all HCPs, the lack of appropriate technology was a barrier to usage. Patients and carers were not aware of the EPaCCS, but were positive about HCPs sharing information.
Conclusion / discussion: This study provides valuable insights into the implementation of EPaCCS. Getting the technology right matters and it is vital that all HCPs can both access and update the information held within the EPaCCS. To support clinical decision-making the information in the EPaCCS needs to be dynamic and reliable.

Abstract number: M-22
Abstract type: Poster

Nurses' Role in Health-Promoting Palliative Care: A Narrative Review

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Background: Varied and innovative system-wide transformations of palliative care models are emerging as health promotion concepts and values shape primary care practice. Compassionate communities, for instance, encompass a broad range of health determinants, and shared partnerships with local community resources. Consequently, the scope of home-based nursing practice is changing. However, although nurses are central to the delivery of palliative home-based care, their role has not yet been described.
Aim: Describe the role of nurses in palliative home-based care from a health-promoting lens.
Method: A narrative review was conducted to map the diversity of health-promoting activities performed by palliative home-based nurses. 58 articles from three databases met the inclusion criteria. Principles of Kellehear's Health Promoting Palliative Care approach were used to complete a thematic analysis.
Results: Values such as autonomy, honesty, security and equity encompass a broad range of nursing activities. These include information sharing about illness and care; caregiver education; physical care; emotional support; and support in the achievement of personal goals towards end-of-life. Overall, medical and technical care activities prevail. When nurses engage with social dimensions of care, their practice is questioned by other healthcare professionals. Unsupported or illegitimated, the

complex nature of home-based nursing practice within community remains poorly understood.

Conclusion: Nursing role in health-promoting palliative care is primarily portrayed as service delivery and individualized care.

The knowledge and practices developed by nurses who engage in collaborations or mobilize local resources within their communities remain invisible. Given that community building is at the forefront of health-promoting palliative care orientation, empirical research should be conducted to describe thoroughly the bridging role nurses could play to support such initiatives.

Abstract number: M-23
Abstract type: Poster

Systemic Oncological Therapy in the Last 30 Days of Life

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Background: There are several end-of-life (EOL) quality indicators, used to study aggressive care near death: use of systemic therapy (ST) in the last 30 (L30DoL) or 14 days of life (L14DoL), ≥ 1 emergency department (ED) visit in the L30DoL, intensive care unit (ICU) admission in the L30DoL and late referral ($<$ 90 days before death) to specialized palliative care unit (SPCU).

Aim: To analyse use of ST (chemotherapy and targeted therapy) in the L30DoL and comparison with our previous studies.

Methods: We conducted a retrospective analysis of data for patients (pts) who died at our institution in 2019 and compared results with 2009 and 2012. We reviewed pts' age, WHO performance status (PS) and chemosensitivity of the disease and evaluated their association with aggressiveness of care (ST in the L30DoL) using Chi-square test.

Results: Among 557 pts there were 53% men and 47% women (median age 68 years, PS ≥ 2 in 76,1%), 47% of pts had chemo-sensitive cancer. In 2019, 17,2% of pts received ST in the L30DoL and 5,6% in the L14DoL. In comparison to 2009 and 2012, there were less pts receiving ST in the L30DoL and L14DoL (39% and 23% respectively and 32,7% and 16,3% respectively). There was statistical significance found between aggressiveness of care and pts' age (younger and older than 65 years) ($p=0{,}006$) as well as chemosensitivity ($p<0{,}001$). The percentage of ICU admissions in the L30DoL was similar in 2019 and 2012 (8,4% and 8,8% respectively) and lower in 2009 (5,3%). SPCU referral was more frequent in 2019 with 19,6% as opposed to 17,9% in 2012 and 6,3% in 2009.

Conclusion: We observed lower use of ST at EOL in the last years and higher referral to SPCU. Pts' age and chemosensitivity were important factors for the decision about ST use in the last 30DoL, SPCU referral wasn't. Still, more frequent SPCU referrals indicate a better implementation of palliative care in everyday oncological practice and better general understanding of its role in complex cases.

Abstract number: M-24
Abstract type: Poster

Validation of the German Version of the Needs Assessment Tool: Progressive Disease – Heart Failure

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Background: The Needs Assessment Tool: Progressive Disease-Heart Failure (NAT: PD-HF) is a tool created to assess the needs of people living with heart failure and their informal caregivers to assist delivering care in a more comprehensive way that addresses real needs that are unmet, and to improve quality of life. So far, the tool has been available in only English and Dutch.

Aims:

1) Translate the original tool into German and culturally adapt it.
2) Assess internal consistency, inter-rater reliability, and test-retest reliability of the German NAT: PD-HF.
3) Evaluate whether and how patients and health care personnel understand the tool and its utility.
4) Assess the tool's face validity, applicability, relevance, and acceptability among health care personnel.

Methods: Single-center validation study, including 70 participants. The tool was using a forward–backward translation. To assess internal consistency, we used Cronbach's alpha. To assess inter-rater reliability and test-retest reliability, we used Cohen's kappa. We interpreted inter-rater and test-retest reliabilities as near-perfect agreement if the kappa was greater than 0.81, as substantial if the kappa was between 0.61 and 0.80, moderate if it was between 0.41 and 0.60, and poor if it was less than 0.40. Face validity was assessed in semi structured interviews.

Results: The translated tool showed good internal consistency (Cronbach's alpha of 0.83). Raters were in substantial agreement on a majority of the questions, and agreement was almost perfect for all the questions in the test-retest analysis. Face validity was rated high by health care personnel.

Conclusion: The German NAT: PD-HF is a reliable, valid, and internally consistent tool that is well accepted by both patients and health care personnel. However, it is important to keep in mind that effective use of the tool requires training of health care personnel.

Abstract number: M-25
Abstract type: Poster

Why Are Patients with Palliative Care Needs Admitted to the Emergency Department? A Retrospective Cohort Study

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Background: The increased number of Emergency Department (ED) visits of adult patients with palliative care needs (APPCN) and the lack of evidence and protocols to identify and manage them can lead to aggressive therapeutic practices at the end of life and reduced quality of life for this group of patients.

Aim: To identify the differentiating characteristics, namely signs and symptoms, of APPCN presenting at the ED.

Methods: Secondary analysis of a retrospective cohort study based on routine clinical data of patients who attended and died in the ED of a

Portuguese urban central hospital (1 Jan to 31 Dec 2016). APPCN were identified according to the National Hospice Organization's terminality criteria and $\geqslant 2$ comorbidities in the Charlson Index. Differentiating signs/symptoms for this group were identified by comparison with patients without palliative care needs (Chi^2 test).
Results: From the 417 patients who died in the hospital's ED in 2016, 301 were APPCN (72.2%), 51.2% female, median age of 82 years (min. 40, max. 102). The most common reasons for ED attendance of APPCN were cardiorespiratory symptoms (49.8%), followed by general symptoms (16.9%), neurological changes (12.6%) and gastro-intestinal or hepatic symptoms (9.3%). When comparing reasons for ED attendance of APPCN with the remaining patients, we observed significant differences ($p<0.001$), most notably cardiorespiratory symptoms were more frequent in APPCN (49.8% vs 31.0%), and neurological changes were less frequent (12.6% vs. 38.1%), when compared with patients without palliative care needs.
Conclusions: Differentiating reasons for ED attendance of APPCN that ended up dying at ED should be considered as indicators to activate specific protocols to treat these patients in an ED setting, similarly to what happens in "fast-track" protocols to identify and manage other high-risk patient groups at the ED.
Main source of Funding: Isabel Levy Research Fellowship by the Portuguese Association of Palliative Care.

Abstract number: M-26
Abstract type: Poster

Measures to Improve General Practitioners' Primary Palliative Care in Germany – A Delphi Studys to Improve General Practitioners' Primary Palliative Care in Germany – A Delphi Study

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Background: Most severely ill and dying people in Germany are cared for in primary palliative care (PPC) by general practitioners' (GP). Although several public health strategies aim at strengthening the role of GPs in providing PPC, it is still challenging for GP teams to integrate PPC into their daily routines.
Aims: A Delphi study with GPs in Germany was conducted to consent measures for improving integration of PPC into GPs' everyday practice.
Methods: The study is part of the junior research group "Primary Palliative Care in General Practice" (ALLPRAX). Measures were developed in a mixed-methods approach (2017-19) and tested in 7 GP practices (2019-20). In 2020, GPs were asked to rate relevance and feasibility of 26 measures on 4-point Likert-type scales. Consensus on measures was defined as a sum percentage of the scorings 'strongly agree' and 'somewhat agree' $\geqslant 75\%$.
Results: 34 GPs participated in two Delphi rounds (response rate 6%). 20 of the initial 26 recommendations reached consensus. The consented measures can be assigned to four main topics: advance care planning with patients, consultation and information for patients and family caregivers, organization of the GP practices and continuing education. Intervention measures for collaboration with other care providers did not reached consensus. Main criticism was a lack of staff and time.
Discussion: The Delphi-consented measures provide valuable support for improving integration of PPC into GPs' everyday practice. The recommendation list for measures can be used free of charge and adapted for use by individual GP teams.
Source of funding: Federal Ministry of Education and Research (BMBF 01GY1610)

Abstract number: M-27
Abstract type: Poster

Integrated End of Life Care in Advanced Congestive Heart Failure: Where Are We Now?

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Introduction: Congestive heart failure (CHF) is an increasingly prevalent terminal illness in a globally aging population. Despite optimal medical management, prognosis remains poor – a fact seldom communicated to patients and/or their families. Evidence suggests numerous benefits of palliative care consultation in advanced CHF but to date, their services remain woefully underutilized.
Objectives: To identify specific challenges to accessing and implementing palliative care in patients with advanced CHF, and to use this information to formulate recommendations for practice.
Methods: Literature review whereby recommendations for practice were formulated on the basis of primary quantitative/qualitative data and consensus expert opinion.
Results: Accessing palliative care services for patients with CHF remains a challenge for numerous factors including prognostic uncertainty, misconceptions about what palliative care is, and difficulty recognizing when a patient is suitable for referral. Strategies to improve access/delivery of palliative care to this population include education and proper discussion about prognosis/goals of care. A team-based approach is essential as we move towards a model where symptom palliation exists concurrently with active medical disease-modifying treatment.
Conclusion: Despite evidence that palliative care has a role in improving symptom control and overall quality of life in patients with end-stage CHF, a multitude of challenges exist and this ultimately hinders access to palliative care services. Education to abolish pre-existing misconceptions about the role of palliative care and a movement towards a team-based approach focused on simultaneous palliative and traditional medical care will undoubtedly improve access to, and benefit from, palliative care services in this population.

Abstract number: M-28
Abstract type: Poster

The Use of a Workshop Format to Develop a Theory of Change for the Integration of Palliative Care into Primary Care for Patients with COPD in Cape Town

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Background: Non-communicable diseases are a major cause of morbidity in low and middle-income countries (LMICs), with chronic obstructive pulmonary disease (COPD) predicted to be third leading cause of death globally by 2030. The majority of patients who require palliative care for advanced disease live in LMICs where there is limited access to palliative care.
Aim: To use a workshop format to bring together stakeholders to discuss and brainstorm the challenges and opportunities for primary care for patients with COPD and their families, in order to plan in intervention to integrate palliative care into standard primary care.
Methods: Stakeholders were invited to a workshop which was held on 8 August 2019. We invited patients, family members, representatives from the Provincial Department of Health, Family Physicians, primary care doctors and nurses, Respiratory Physicians and Palliative Care Physicians. The meeting was facilitated by an external researcher experienced in the Theory of Change Workshop format.
Results: The facilitated discussion explored key challenges and a desired impact, with the identification of and discussion into potential pathways to achieving the desired impact. The process was considered to start with awareness for all stakeholders, to include capacity building and training, in order to facilitate detection and diagnosis of physical and psycho-social and spiritual distress, with a clear pathway for care in the

primary care setting. Referrals were considered important: referrals within the facility, to tertiary care, and to community care workers. At all levels increased patient and family educational support was considered necessary.

Conclusion: The Theory of Change Workshop format is an accessible approach that can be used to gather a number of stakeholders, including patients and family members, to discuss and gain consensus on how to plan an intervention for patients with palliative care needs.

Abstract number: M-29
Abstract type: Poster

Hospice Care Provides Reduction of Life-sustaining Treatment in Advanced Cancer Patients in End-of-Life Care

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Background: Many quality indicators of hospice care had been studied in end-of-life care, but not ever included excessive life-sustaining treatment.

Aim: The aim of this analysis is to evaluate the effect of hospice care services on improving patients' autonomy in decision making, polypharmacy and excessive life-sustaining treatment in the life-limiting cancer patients.

Methods: This was a retrospective cross-sectional study in a single medical center in Taiwan. Patients with advanced cancer dying in 2010-2019 were included, and those dying before the age of 20 or dying on the same day as hospice care had involved in end-of-life care were excluded. Patients were divided into three subgroups: hospice ward admission, hospice shared care, and no hospice care involvement. We reviewed their clinical characteristics, place of death, type of DNR consent and life-sustaining treatment, within 28 days of death.

Results: A total of 8719 patients were enrolled, and 2097(24.05%) had admitted to hospice ward, 2107(24.17%) received hospice shared care, and 4515(51.78%) had no hospice care intervention. Those admitting to hospice ward had a significant higher incidence of dying in the hospital (80.83%, vs 50.17% and 45.16%, $p<0.001$) and signing the DNR consent by themselves (48.58% vs 26.22% and 22.38%, $p<0.001$). Within 28 days before death, those receiving hospice care had a significant reduction in numbers of medication administration as well as the imbalance amount of input and output fluid, the amount of intravenous fluid hydration and the antineoplastic drug administration.

Conclusions: Our study showed that hospice care in terminal stage provided higher quality of life and improved patients' autonomy in decision making, reduction of polypharmacy, antineoplastic drug administration and excessive life-sustaining treatment; the influence was more significant when getting closer to the end of life.

Abstract number: M-30
Abstract type: Poster

Assessing Palliative Care Needs in an Internal Medicine Ward: The Role of IPOS. A Cross-sectional Study

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In the past decades we have seen a progressive transition from acute to chronic illnesses with high comorbidity and frailty. Nevertheless the patient's need assessment are still based on a Medicine centered on acute diseases. Aim of this study is to evaluate, in a Division of Internal Medicine, the physical, psychological, existential, social needs that the scientific literature showed to be relevant for patient's quality of life, in patients affected by incurable illnesses.

The cross sectional study has considered 51 patients, hospitalized in an Internal Medicine ward for at least 3 days, on 16*th* October 2019. Patients' physicians were administered the Surprising Question tool: "Would you be surprised if this patient will die in the next 12 months?". For 30 patients the answer was yes. Those were investigated with the NECPAL Tool, with the aim to identify people with palliative care needs. This tool pointed out that palliative care needs was present in 27 patients. These patients were then administered a validated questionnaire - the Integrated Palliative care Outcome Scale (IPOS) - to measure the weight that each patient gives to his symptoms and needs. Furthermore, we looked for a relationship between weight of needs, Performance Status according to the Australia-modified Karnofsky Performance Scale and Phase of Illness.

The weight of needs evaluated through IPOS was much heavier than physicians in charge had imagined. Indeed, we observed a definite correlation between IPOS and both AKPS and Phase of Illness. A second outcome was that the IPOS questionnaire triggered an empathic communication between patient and doctor. Finally, using these tools physicians recognized needs and symptoms unappreciated at the beginning or during the inpatient staying. In particular, it was surprising the great relevance of symptoms attributable to the psychological/spiritual/relational sphere, felt by the patients as relevant as the more easily recognized physical needs.

Abstract number: M-31
Abstract type: Poster

General Practice Opens the Door to Primary Palliative Care in Italy: An Italian Version of Red Map

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Background: The Italian College of General Practitioners and Primary Care has formed a task force which has the aim of teaching the principles of Primary Palliative Care in the next three years, in particular: early identification, multidimensional evaluation, plan of care and communication. A validated Italian version of SPICT is now available as a tool for early identification. The RED MAP is a useful clinical six step communication guide to assist with discussions with individuals and their families about planning treatment and care, death and dying.

Aim: The aim of the project is to translate the RED MAP and adjust it to the Italian cultural context.

Methods: We started this project by identifying an Italian acronym that encloses all the subsequent steps of the communication process. We chose "CADUCEO", an historical symbol of medicine. The RED MAP has been translated by a team of Italian GPs with the help of a native speaking English doctor. The draft was evaluated by an independent multidisciplinary panel which includes a nurse, a bioethicist, a psychologist, and a specialist in Palliative Care. The final version will be shared with a group of GPs which will test it in Clinical Practice for three months: a short questionnaire will be used to gather opinions and suggestions.

Results: Due to the COVID emergency we are still working on this project, we plan to reach a final version of the tool in Summer 2021 and to publish it in a position paper by S.I.M.G on Primary Palliative Care improvement in Italy.

Conclusion/Discussion: In Primary Palliative Care the communication with the patient and the caregiver is fundamental for developing an effective care plan. RED MAP is a useful tool to guide the conversation. Our project aims at translating RED MAP into Italian, adjusting it to the Italian cultural context, and to validate it in daily Clinical Practice.

Abstract number: M-32
Abstract type: Poster

Family Physicians' Perspectives about Their Role in Palliative Care: Double Online Focus Groups

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Background: Patients with chronic illness are managed in primary care over a long period of time. Family Physicians (FP) can play a role in Palliative Care (PC) delivery. However, knowledge about what FP think about their role in PC is still lacking.

Aim: This study aimed to understand FPs' perception about their role in PC and what would be the most adequate training program according to their needs.

Methods: Two online focus groups were conducted between May and June 2019 in Portugal, one involving 9 FP and another with 10 FP trainees. Each group had two facilitators. The discussion followed a semi-structured topic guide developed based on a literature review and on researchers' inputs. There were three main topics (FPs' role in PC, the importance of training in PC, training models in primary care), each with 3-5 open-ended questions. The data were analysed using thematic analysis.

Results: Trainees' group had first to last year trainees, 80% ♀. FPs' group had 4.56y mean time of practice, 55.6% ♀. FP believe they gather a skillset important for PC, mainly by understanding patients beyond symptoms. FP can help in the early identification and in symptom management of less complex patients. Participants flagged some barriers, namely that there are many patients without a FP and that each FP must manage big list of patients (1600-1900). The need for training in PC was consensual and the topics that mattered most were clinical training (patients' identification and symptom management), communication (bad news and grief) and understanding the national PC network. The most adequate training structure seemed to be a short program (2 days) addressing theoretical concepts, discussing clinical cases using roleplay and integrating a practical component.

Conclusion: FP at different career stages recognise they can play an objective role in PC. By addressing their perspectives, we may help materialise this potential and thus develop a broader PC network.

Abstract number: M-33
Abstract type: Poster

Attitudes of Patients and Informal Caregivers on Early Palliative Care, in New Primary Settings, in Attica, Greece: A Qualitative Approach

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Background: Early palliative care at disease diagnosis can be integrated in primary care. In Greece, a reformation on primary care is underdevelopment; new units introducing an interdisciplinary team are evolving.

Aim: To explore palliative care patients and caregivers' perceptions and needs, early at the disease trajectory, at those settings.

Methods: Serial qualitative semi-structured interviews were conducted with 35 patients and 33 caregivers. 12 patients with cancer, 8 with dementia/frailty and 15 with organ failure were purposively recruited, until thematic saturation. All had symptom burden.Thematic analysis with manually coding was used. Ethics approval was obtained from the Hellenic Association of Research and Education in Primary Care; written informed consent was obtained.

Results: Three major themes were identified: 1) Multidimensional needs including physical, psychosocial, spiritual, practical, economical and informational; caregivers were mainly female relatives, with physically demanding, psychosocially stressful and economically restrictive experiences, 2) Communication at diagnosis, plan and coordination of care, as well as team-based holistic symptom management were considered vital. Control to cope and adapt to a changed life, a new meaning and functioning was achieved by providers, treating the family as a whole, 3) The nature of the underlying condition defined the early needs addressed and the team roles. Patients and caregivers with cancer and dementia/frailty reported mainly psychosocial and practical needs. Team work was crucial to meet the needs of the elderly. The family physician was the most important for patients with chronic conditions and distressing physical symptoms.

Conclusions: Palliative care patients and caregivers at diagnosis have multidimensional needs. A primary care interdisciplinary team can integrate early palliative care in the community. The nature of the underlying condition defines the form of care.

Abstract number: M-34
Abstract type: Poster

When Ostomy Is a Palliative Condition: The Experience of an Oncology Institute

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Background: In Portugal, approximately 15000 people have an ostomy and 80-90% of them are due to oncological diseases. In terms of self-care and acceptance, an ostomy implies a transition and demanding adaptation process. Being a mutilating surgery can lead to many complications, such as changes in body image and lifestyle, affecting psychosocial relationships. In Palliative Care (PC) patients the prevalence of ostomy is unknown.

Aims: Identify the prevalence of ostomies in palliative cancer patients (PCP), the incidence of ostomy complications and the disease course's point at which the ostomy is built.

Methods: This descriptive and exploratory study included 124 adult PCP admitted to the PC unit of a Portuguese oncology institute, in 2020. The data about ostomies and surgery time from this non-probabilistic sample was collected in January 2021, through clinical process analysis. Data analysis was with descriptive statistics software. This study complies with ethical procedures.

Results: Results revealed that 26.2% of PCPs have an ostomy, most were performed in an advanced disease state and were elimination type. 41% of ostomies were performed electively in patients with the advanced disease before reach PC service. In this service, 14% of PCPs were proposed to ostomy due to food intake. The food-related complications in this population have an incidence of 16%, values of 35% in urinary/intestinal elimination and 46% in breathing and required therapy. Haemorrhages, peri-ostomy skin lesions, stenosis or prolapse and inadequate devices are the main complications, requiring support from ostomy therapists.

Conclusion / discussion: The incidence of complications is frequent, being higher in respiratory ostomies, and associated with loss of self-care capacity. To improve self-care, quality of life and complications control is convenient earlier support to patients and family, preferable when ostomy procedure is suggested.

Abstract number: M-36
Abstract type: Poster

The Portuguese Patient Dignity Question: A Cross-sectional Study of Palliative Patients Cared for in Primary Care

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Background: The Patient Dignity Question (PDQ) is a clinical tool developed with the aim of probing personhood, reinforcing dignity and enabling health care providers (HCPs) to see patients as people and not solely based on their illness.
Aims: To study the acceptability and feasibility of the Portuguese version of the PDQ (PDQ-PT) in a sample of palliative care patients cared for in primary care (PC).
Methods: A cross-sectional study using 20 palliative patients cared for in a PC Unit. A post-PDQ satisfaction questionnaire was developed.
Results: Twenty participants were included, 75% were male; average age was 70 years old. Patients found the summary accurate, precise and complete; all said they would recommend the PDQ to others and want a copy of the summary placed on their family physician's medical chart. They felt the summary heightened their sense of dignity, considered it important that HCPs have access to the summary and indicated that this information could affect the way HCPs see and care for them. The PDQ-PT's took seven minutes on average to answer; and 10 minutes to complete the summary.
Conclusion: The PDQ-PT is well accepted and feasible to use with palliative patients in the context of PC and seems to be a promising tool to be implemented. Future trials are now warranted.

N Posters Communication

Abstract number: N-03
Abstract type: Poster

Dealing with Desire to Die in Palliative Care. Evaluation of a Communication Intervention

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Background: Many patients in palliative care (PPs) develop at least a temporary desire to die (DD), partly associated with psychological distress. Although health practitioners (HPs) are often confronted with DD, uncertainty remains as to the right response. Therefore, a training and a semi-structured clinical approach (SSCA) were developed. In a recent study, the SSCA was finalized and HPs were trained in dealing with DD. Trained HPs were asked to proactively address DD with their PP. Effects of these conversations were evaluated.
Aims: To evaluate the effects of a DD-conversation on PPs.
Methods: In a sequential mixed-method design, standardized interviews with PPs were conducted with validated questionnaires on depression, DD, death anxiety, relationship with HPs and hopelessness. After the first standardized interview (t0), trained HPs had a DD-conversation with their PPs. Two (t1) and six weeks later (t2) the standardized interview was repeated. Results were analysed using descriptive statistics. Qualitative interviews were conducted with a patient sub-sample and analysed using content analysis.
Results: From 4/2018 to 3/2020, 43 HPs suggested 172 PPs of which 85 participated in t0. A complete data set (t0, DD-conversation, t1, t2) was collected for 47. Qualitative interviews were conducted with 13 PPs. PPs were 57% female, had a mean age of 69 years and heterogenous diseases (59% oncological, 13% neurological, 28% others). PPs depression severity decreased significantly from t0 to t1 ($p = .001$; effect size $d = .44$). At t2, this difference lost significance due to small sample size. All other outcomes showed positive trends. Qualitative data underlines positive effects: "*Then it became clear to me that (. . .) I think about death in a completely different way. (...) I feel cared for, covered, so to speak, and if I have new ideas, I can address them*."
Conclusion: DD-conversations did not lead to a worsening in any outcome in PPs; but may alleviate depression.

Abstract number: N-04
Abstract type: Poster

Association between Perceptions of Involvement in Advance Care Planning and Emotional Functioning in Patients with Advanced Cancer: Results of the Prospective, Multicenter, Observational eQuiPe Study

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Background: Advance Care Planning (ACP) is positively associated with the quality of end-of-life care, but its impact on quality of life is ambiguous.
Aims: To investigate the association between perceptions of ACP involvement and emotional functioning in patients with advanced cancer.
Methods: This study analyzed baseline data from the eQuiPe study, a prospective, multicenter, observational study on quality of care and quality of life in patients with advanced cancer in the Netherlands. Patients with metastatic solid cancer were recruited between November 2017 and January 2020. Patients' perceptions of ACP involvement were measured by three statements on patients' involvement in decisions about their future medical treatment and care

(1) and the engagement of their relatives
(2) and physicians
(3) with their preferences regarding their future medical treatment and care.

Emotional functioning was measured by the EORTC-QLQ-C30. A linear multivariable regression analysis was performed on baseline data of 1,001 patients while taking gender, age, migrant background, education, marital status, and symptom burden into account.

Results: The majority of 1,001 patients with advanced cancer reported that they were as much involved as they wanted to be in decisions about their future medical treatment and care (87%). Most patients felt that their relatives (81%) and physicians (75%) were familiar with their preferences for their future medical treatment and care. Patients scored a mean of 75(SD 17) on their perceived involvement in ACP. A positive association was found between patients' perceptions of ACP involvement and their emotional functioning (b=0.162, $p<0.01$) while controlling for above mentioned confounders.

Conclusions: Perceptions of involvement in ACP are positively associated with emotional functioning in patients with advanced cancer. Future studies are needed to further investigate the effect of ACP on emotional functioning.

Abstract number: N-05
Abstract type: Poster

Dealing with Desire to Die in Palliative Care: Evaluation of a Training Program

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Background: Although health practitioners (HPs) are frequently confronted with desire to die (DD) in palliative care, they remain uncertain regarding the right response. Therefore, a training and a semi-structured clinical approach (SSCA) were developed. Within a mixed methods study, the SSCA was finalized and HPs were trained in using it when dealing with DD.

Aims: How do HPs report their self-confidence, knowledge, skills and attitude in dealing with DD before and after the training?

Methods: Implementation of two-day multi-professional trainings on dealing with DD, including an introduction to the use of the SSCA. HPs assessed their self-confidence, their knowledge of DD (functions and backgrounds, legal framework, distinction from suicidality), their skills in dealing with it (proactive approach, recognition of own stress) and their own attitude towards DD by means of a questionnaire before (t0), immediately after (t1) and one year after (t2) completion of the training. In t2, open questions were asked about the use of the SSCA. Trained HPs were asked to have DD-conversations with patients receiving palliative care and to reflect on them in writing.

Results: From 03/2018 - 01/2020, 103 HPs from different settings participated in 12 trainings. On average, they had 12 years of professional experience and were 48 years old, 75% were women. Self-confidence in dealing with DD increased significantly ($p = .000$, $d = .74$), this effect remained stable over one year ($p = .000$, $d = .072$). Knowledge of DD (t1: $p = .000$, $d = .84$; t2: $p = .000$, $d = .81$) and the ability to address them proactively (t1: $p = .022$, $d = .25$; t2: $p = 0.001$, $d = .51$) showed similarly stable significant improvements.

HPs described applicating training contents in patient conversations as well as the reflection of these conversations as enriching.

Discussion / conclusion: The long-term increased self-confidence of HPs in dealing with DD confirms the effectiveness of the training.

Abstract number: N-07
Abstract type: Poster

Palliative Care Research Knowledge Transfer - A Website Analysis of Comprehensive Cancer Centers

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Background: Comprehensive Cancer Centers (CCC) provide cutting-edge cancer medicine and research as well in the field of supportive and end-of-life care. Knowledge transfer, networking and patient and public involvement require visibility of research activities. How visible is palliative care research on CCC websites?

Aim: Mapping web presence of palliative care research on German CCC websites.

Methods: Website analysis of CCC sites supported by the German Cancer Aid. Using a systematic content analysis two researchers (JB, SG) independently screened 20 websites in February 2021. A category system (e.g. research focus, number of projects, methods, publications, language, number of submenus) was established in advance. Relative frequencies, mean, median, minimum and maximum were evaluated.

Results: 12 palliative care departments have a drop down menu for palliative care research. In average, those had 3.8 submenus (median 3.0; min=0; max=10). 10 sites provide information on individual research projects (current or completed). In median, 6.5 projects were presented (min=0; max=28). The research teams' research focus is specified on 12, the method expertise on 8 websites. 5 websites use the English language for project title, description or working group introductions, in addition to the German language. Publications of the palliative care departments are listed on 8 of 20 websites.

Conclusion: Palliative care departments may miss opportunities to provide information online about their research interests for networking and possible research cooperation, especially for international findability. Defining minimum standard content on palliative care research on CCC websites could improve visibility.

Funding: None.

Abstract number: N-08
Abstract type: Poster

Empowerment of Patients with Copd and/or Heart Failure to Express their Perspective to Healthcare Professionals: The Development of a Supportive Toolkit

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Background: Patient's perspective on their health, well-being and care is important to deliver person-centred care. This perspective, including knowledge, experiences, goals, needs, priorities and preferences, is not always expressed to healthcare professionals. Interviews and focus group sessions with patients, relatives and healthcare professionals were performed. This resulted in the identification of three challenges to communicate patient's perspective in consultations; 1. to express who you are as a person and what is important to you, 2. to share your knowledge about living with the disease and what does or does not work for you, 3. to talk about prognosis and end of life.

Aim: To develop a prototype toolkit for patients with COPD and/or heart failure enabling them to express their perspective to healthcare professionals.

Method: Four co-creation sessions were used to develop a prototype toolkit. Two sessions to define the ideal situation and generate potential solutions and two sessions to test prototype toolkits.

Results: Twenty four unique individuals participated in the co-creation sessions. Ideal situation; all participants are prepared for the consultation, patients are more in the lead during the conversation, patients are known as unique individuals by healthcare professionals. Potential solutions; a website with relevant and reliable information and links to existing tools, a personal file to be used in combination with the medical file, a questionnaire about the person and the disease to fill in and return before the consultation. Toolkit tests; easy to use and understand for independent use at home, ability to choose one or more tools based upon individual needs and preferences, physical and digital toolkit to meet different user preferences.

Conclusion: It was possible to develop a prototype toolkit in co-creation with patients, relatives and healtcare professionals. Additional research is needed to test and implement the toolkit.

Abstract number: N-09
Abstract type: Poster

Is Prognosis Discussed with Patients who Have Peripheral Arterial Disease? A Systematic Review

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Background: Peripheral arterial disease (PAD) is a common condition estimated to affect 20% of people aged 75 and above. Evidence suggests that 10% of people who have PAD are in their last year of life. We therefore wanted to determine how often prognosis is discussed with this group of patients.

Aims: To systematically review evidence on whether prognosis is discussed with patients who have PAD, and if so at which stage in their disease trajectory.

Methods: We searched CINAHL, Embase, Medline, PschINFO databases until 16th July 2019 using a predetermined search strategy. Two authors independently completed the systematic literature search, reviewed and extracted data from retained texts. Articles were assessed using Joanna Briggs critical appraisal checklist, suitable for the study designs.

Results: 14,989 articles were identified of which 23 abstracts were assessed for eligibility and 2 papers were retained for narrative synthesis. The quality of the 2 retained studies was moderate but the study designs as defined by the Clinical Outcomes Group were of low quality: a case series and a report with a total of 31 patients. There were no documented discussions of prognosis in either of the studies. Palliative care was discussed with 41.9% of patients (n=13) and 87.1% (n=27) of close relatives, but detail regarding the content of the conversations was not provided. The interval between decision to palliate and death ranged from 24 hours to 7 weeks.

Conclusion: Patients with PAD are known to have a reduced life expectancy related to the presence of underlying coronary, renal and cerebral artery disease, and 10% are estimated to be in the last year of their life. To ensure that high quality patient care is delivered, initiating conversations about prognosis is essential. This systematic review identified a lack of evidence to demonstrate that this is currently happening in clinical practice. Further research should aim to explore the reasons behind this.

Abstract number: N-10
Abstract type: Poster

Interdisciplinary Collaboration in Nursing Home Teams: A Generic Qualitative Design Using Observations

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Background: Nursing home teams provide care to patients with a life-limiting illness with physical, psychological, social, and spiritual needs. An interdisciplinary team approach ensures attention for all dimensions to ameliorate patient outcomes, team effectiveness, and team satisfaction.

Aim: To explore interdisciplinary collaboration in nursing home teams.

Methods: A generic qualitative design in a somatic and psychogeriatric ward of a nursing home. Data was collected through participant observations schemes consisting of descriptive, focused, and selective observations of collaborative moments and subsequent validation of the observations in conversation with professionals. The Bronstein model of Interdisciplinary Collaboration was used as a theoretical framework. Data was analyzed thematically.

Results: Collaborative moments (N=54) were: multidisciplinary consultations, handovers, patient visits, and ad hoc consultations. Observations included 24 unique caregivers of 8 professions. Validating conversations were held with 11 care providers from 9 professions. Four themes emerged: interdisciplinary communication, accessibility of caregivers, distribution of responsibilities, and interests of caregivers and patients. There was no team identity, caregivers mainly focused on their discipline and there were no multidisciplinary consultations with all caregivers. Decisions were made by physicians and psychologists and communicated with a RN/nurse assistant. No shared decision-making was observed.

Conclusion: Collaboration in nursing home teams has a multidisciplinary character. To improve collaboration we recommend: structural involvement of paramedics, planned discussions of common interests, and scheduled consultations for the entire team. Practical guidelines are needed to shift from multidisciplinary towards interdisciplinary collaboration and ameliorate the quality of patient care.

Funding: Netherlands Organization for Health Research and Development

Abstract number: N-11
Abstract type: Poster

The Essentials of Communicating about Approaching Death: Development of a Communication Model

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Background: Caring for dying individuals is an integral aspect of care, however training and exposure to conversations with dying patients and their families is almost inexistent during medical and nursing education. Thus, many health professionals lack the skills to communicate about imminent death causing long-lasting impact to all involved.

Aims: We aimed to develop a communication model for health professionals to engage in conversations about approaching death with patients and families.

Methods: A systematic review of literature as well as experiences of palliative care (PC) experts built the model's basis. The initial model was exposed to international PC experts for feedback and revised for discussion in five focus groups with medical students, physicians, nurses, bereaved relatives, and patient representatives. After thematically analyzing focus group data, we reviewed the model and presented it for confirmation to communication experts.

Results: Reflection on own attitudes and feelings towards death as a professional and as an individual are central to the model. The model contains three main parts: 'Before' includes recognition of the dying phase and preparation of the talk. 'During' focuses on setting the stage for communicating about dying, exploring the patient's and family's view, as well as major concerns and needs regarding the current situation and the dying process, establishing shared goals for the last days of life, defining a care plan for the dying process, and summarizing and exiting the conversation. 'After' includes debriefing, self-reflection and self-care.

Conclusion: This is the first model of communication about approaching death developed with key stakeholders. With specific steps and practical advice regarding relational aspects of conversations about dying and death, verbal and nonverbal communication skills and self-care strategies, the model can significantly contribute to medical and nursing education.

Funding: Swiss Cancer Research.

Abstract number: N-12
Abstract type: Poster

Rubbing Minds Together: A Grounded Theory Study to Explain the Process of Expressing End of Life Care Wishes and Preferences amongst Patients with Advanced Incurable Cancer and their Family Members

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Background: Navigating end-of-life communication is fraught with difficulty necessitating an enhanced cultural competence. Despite an increasingly multicultural world, little is known about how African patients with terminal illness and their family members engage in end-of-life discussions or express their care preferences.

Aim: To construct a theoretical explanation of the process of expressing end-of-life care wishes and preferences among Nigerian patients diagnosed with advanced incurable cancer and their family members.

Methods: Using a constructivist grounded theory approach 8 patients with advanced-stage cancer and 6 family caregivers participated in an open-ended interview exploring views and experiences of end-of-life care family communication. Data were collected between August 2017 and September 2018 in a palliative care unit in Northern Nigeria and were analysed using grounded theory techniques.

Results: Rubbing minds together is a theoretical explanation for the dynamics of communication between patients and their family members within the context of a family-centric society. It represents a negotiation in resolving differences of opinion and engaging in conversations about end-of-life care preferences. It comprises a triad of interlinked conceptual categories: controlling to seek relief, collaborating, and enduring. Controlling to seek relief signifies the Nigerian patient's commitment to personal involvement in end-of-life discussions. Collaborating acknowledges the need for family involvement in this process, while enduring represents the individual and collective display of resilience by patients and family members.

Conclusion: Nigerian patients and their family members actively engage in 'rubbing minds together' in order to reach consensus on end-of-life care wishes. This theory may have wider implications for the delivery of culturally sensitive end-of-life care and advance care planning in Africa and other collectively focussed societies.

Abstract number: N-13
Abstract type: Poster

Nurses' Involvement in End-of-Life Discussions with Incurable Cancer Patients and Family Caregivers: An Integrative Review

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Background: Nurses are among the healthcare professionals who spend the most time with patients and their families and they thereby have the opportunity to facilitate end-of-life discussions. However, limited knowledge exist of nurses' involvement in end-of-life discussions.

Aim: To review current evidence of nurses' involvement in end-of-life discussions with incurable cancer patients and their family caregivers.

Methods: We conducted a systematic integrative review in accordance with PRISMA guidelines: PROSPERO, registration number: CRD42020186204. Data sources: CINAHL, Medline, PsycInfo, Embase. We searched for primary research between 2010-2020. Data analysis was based on Whittemore and Knafls method.

Results: Of 3271 references, we found 15 eligible articles: Qualitative (n=12) and quantitative (n=3). The data analysis resulted in four themes: 1) *Nursing roles*, 2) *Trust building*, 3) *Nurse competences* and 4) *Medical issues.* Nurses had different roles; the advocating, supporting and reframing roles, and an undefined task e.g. in medical consultations. The profession acted as an intermediary between patients and physicians and helped patients initiate discussions. They also reframed stigma around palliative care. However, they sometimes felt they had an unclear task, not knowing their role in the discussion. Lack of competence could be a barrier to initiate discussions. Furthermore, it was important for the nurses to know the patients and families but they also perceived the families as time consuming.

Conclusion: This study shows that nurses have defined roles, as well as unclear tasks. Nurses have insufficient competencies to engage in the discussions, and interventions that can help nurses develop competences across identified roles are needed. Families could pose barriers to end-of-life discussions in some situations. Future research is required to develop effective ways to ensure that families are involved throughout the cancer trajectory.

Abstract number: N-14
Abstract type: Poster

Effects of a Theory-based ACP Intervention for Nursing Homes: A Cluster Randomized Controlled Trial

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Background: The uptake of advance care planning (ACP) in routine nursing home care is low. Through extensive literature review, theoretical development, and stakeholder involvement, we developed the ACP+ intervention program.

Aims: To evaluate the effects of ACP+ on the knowledge and self-efficacy (confidence in own skills) concerning ACP of nursing home care staff.

Methods: A cluster randomized controlled trial, conducted between February 2018 and January 2019 (NCT03521206, clinicaltrials.gov) in nursing homes in Flanders (Belgium). ACP+ is a multi-component intervention aimed at training and supporting nursing home staff and management in implementing ACP in routine nursing home practice through a train-the-trainer approach over eight months. Fourteen nursing homes were randomized using a matched-pairing strategy, seven received ACP+, seven followed usual practice. We conducted intention-to-treat analyses using linear mixed models.

Results: 694 of 1017 care staff (68% response rate) at baseline and 491 of 989 care staff (50%) post-intervention (at 8 months) returned questionnaires. Post-intervention, care staff's self-efficacy concerning ACP was significantly higher in the intervention than in the control group (mean difference for group*time interaction 0.57; 95%CI 0.20 to 0.94; p=0.003; Cohen's $d = 0.30$). ACP knowledge (mean ratio for group*time interaction: 1.04; 95%CI 0.95 to 1.15; p=0.339) did not differ significantly between groups post-intervention.
Conclusion: The ACP+ intervention for nursing homes improved care staff's self-efficacy in performing ACP but not their ACP knowledge in our sample. Considering the comprehensive and multi-component training approach used, these effects were smaller than expected. Reasons for this may be related to the chosen follow-up period, outcomes and measurements, or to the intervention itself and its implementation. The latter was evaluated in an in-depth mixed-method process evaluation.

Abstract number: N-15
Abstract type: Poster

Where Do We Go to Get Cancer? Non-cancer Patients Entering their Last Year of Life Get Poor Communication

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Background: There are commonalities in the prevalence of symptom burden and problems across cancer and non-cancer patients in their last year of life. Entering this phase of life essentially depends on transparent and proactive communication about the lethal course of the disease.
Aims: To compare communication experiences on diagnosis, prognosis and dying of patients in their last year of life between cancer and non-cancer.
Methods: Cross-sectional post-bereavement survey, utilizing an adapted German version of the VOICES-questionnaire. Differences in the reported experiences of relatives of cancer and non-cancer decedents were assessed using a two-sided Pearson's chi square test.
Results: From a total sample of 351, relatives of 209 cancer patients and 142 non-cancer patients completed the questionnaire. Among the non-cancer-conditions, the main cause of death was due to neuro-psychological psychiatric diseases (63.4%), followed by cardiovascular diseases (61.3%), and respiratory diseases (43.7%). Relatives reported that 60.2% of non-cancer-patients were not informed that their disease could lead to death ($p<0.001$), while only 21.7% of the cancer patients had no knowledge of it. While cancer patients were more often informed by the hospital doctor (p=0.050), patients with a non-cancer disease received information more often by the GP (p=0.015). 66.9% of non-cancer and 41.6% of cancer-patients were not informed about their imminent death ($p<0.001$).
Conclusion / Discussion: Only one in three non-cancer-patients was entering the last year of life knowing about the lethality of their disease. Due to the longer course of non-malignant diseases and their less predictable trajectory, palliative care needs are not always identified and prognostic communication is poor. A timely identification and transparent proactive communication about prognosis and the possibility of dying so that wishes and preferences can be met is vitally important.

Abstract number: N-16
Abstract type: Poster

How Palliative Care Professionals Interact with Other Professionals?

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Introduction: Palliative care continues to be misunderstood within the world of healthcare. Palliative care professionals are key agents for promoting a better understanding of their field. This study aims to examine the messages, both implicit and explicit, that palliative care professionals transmit about themselves to other health professionals.
Methods: This study is an ethnographic exploration of the interactions of palliative care professionals in their daily work. An inductive thematic analysis was developed from 242 hours of observation of the daily work practices of palliative care professionals, focusing on their interactions with others. The data was coded without predefined categories, and the analysis was performed independently by two researchers.
Results: Palliative professionals communicate that they are part of an active team working in an organised manner. They value and take pride in their work. Despite the intensity of their work, these professionals are always available to others, to whom they demonstrate a clear professional identity. They convey their expertise in alleviating suffering, respectful behaviour and collaborative ability.
Conclusion: Professionals, in their daily work, communicate through their messages the essence of palliative care. This study suggest that PC professionals adopt explicit methods of conveying their contributions to their patients, their families and the health system. Through discussion and explanation, professionals promote the social recognition that PC deserves.

Abstract number: N-17
Abstract type: Poster

Mind your Words: The Patient Perspective on Communication that Harms and Heals in Advanced Cancer

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Background: *'Do no harm'* lies at the heart of medicine. Many medical complaints, also in advanced illness, are about communication. Little is still known about which *specific* face-to-face communication has the potential to harm patients.
Aims: We aimed to explore from a patient perspective which communication can harm and which alternatives can help in advanced cancer.
Methods: An online survey design was used. Based on a scoping literate search and patient/clinician/researcher input, a questionnaire was created and piloted. Patients with incurable cancer (n=74) indicated for 20 situations (domains: informing, empathy, decision-making) whether they perceived communication herein as potentially harmful; and if so, they provided examples as harmful and helpful (yes/no); and provided alternative examples (open comments). Results were quantitatively (yes/no: descriptive) and qualitatively (open comments: following principles of content analysis) analyzed.
Results: Communication can harm within patients' *Need to know* (information-provision; prognosis; decision-making) and *Need to feel known*

(empathy). Harm occurs in various ways; e.g. by making vague instead of concrete promises (92%); being too directive in decision-making (qualitative, therefore no %); complimenting without space to disagree (76%). The harmfulness of some situations remains disputed; e.g. introducing the option of refraining from anti-cancer therapy (49%); giving detailed (prognostic) information (60%). *Ask the patient* seems a precondition for helpful communication.

Conclusion: We provide a patient-perspective on harmful communication behaviors and offer practical tools to overcome them in advanced cancer. Both easy-to-avoid (e.g. *patient* versus *Mrs X*) and delicate (e.g. introducing no anti-cancer therapy) pitfalls are described, for which *Ask the Patient* might help. Research is needed on harmful/helpful behaviors' effect on patient outcomes, to use communication's power for the best.

Abstract number: N-18
Abstract type: Poster

Decisional Control among Patients with Advanced Cancer in a Tertiary Cancer Center in Jordan

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Background: Understanding cancer patients' preferences toward decisional control is essential toward improving patients' quality of care and satisfaction. In Jordan, the decisional control preference research is scarce.

Aims: To identify the frequency and predictors of decisional control preferences, identify the concordance between the decision control preferences and actual decisional making and its impact on patients' satisfaction.

Methods: Prospective survey was conducted for patients with advanced cancer receiving palliative care in an outpatient setting. Multivariate logistic regression models estimated the effects of patients' socio-demographic, clinical characteristics on their decision-control preferences using Control Preferences Scales, and the Satisfaction with Decision Scale.

Results: 200 patients completed the survey. The median age was 49.8 years (IQR 39.8, 61.9). 115(57.5%) were females. The most common cancer was gastrointestinal cancer 50 (25.0%). Majority of patients 81(40.5%) preferred passive decisional control; 70 (35%), 49 (24.5%) preferred shared and active respectively. Of those who preferred passive role; (42.7%) preferred to leave their decision to their involved physician. The odds for preferring a passive role significantly increased with lower education status (OR=1.444, P=0.042) and being female (OR=1.037, P=0.003). Actual decision-making and preferred decision control concordance was significant ķ coefficient 0.69 (0.59–0.79 CI). Overall, 164 (82%) patients were satisfied with their decisional making process.

Conclusion/Discussion: More patients preferred the passive role; most of them tend to leave the decision to their involved Physicians. The educational level and gender were the only significant predictors for passive decisional control. Further studies are needed.

Funding: This work is supported by MD Anderson Sister Institution Network Fund & Intramural Grant from King Hussein Cancer Center.

Abstract number: N-19
Abstract type: Poster

Challenges of Advance Care Planning in Indonesia: Qualitative Study of Healthcare Professionals' Perspectives

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Background: Our recent systematic review on advance care planning (ACP) in Asia showed no study from Indonesia, a country characterized by the centrality of religion in the care for patients with serious illness and the family's essential role in decision-making.

Aim: To explore the perspectives of Indonesian HCPs about ACP for patients with cancer.

Methods: Four focus-group interviews with nurses and physicians from the national cancer center and a national general hospital were held in July and August 2019. We developed a topic guide to explore Indonesian HCPs' perspectives towards ACP for patients with cancer. Thematic analysis with analytical rigor enhanced by dual coding and exploration of divergent views was employed.

Results: We included 16 physicians and 16 nurses. We identified eight main themes: (1) ACP is interpreted as an end-of-life conversation; (2) ACP is generally considered necessary; (3) ACP is not in line with local norms such as taboo nature of death-related conversations and family-centered decision making; (4) HCPs' lack of confidence to conduct ACP; (5) the health care system is not ready for ACP; (6) missed opportunities to engage patients in ACP; (7) belief in providence is a barrier for future-planning-related conversation; (8) validation of patients' religious beliefs is an essential initial step to engage patients in a conversation about value exploration.

Conclusion: Capacity building for ACP in Indonesia requires education about what ACP entails, training to improve HCPs' confidence, integrating ACP in the health care system, and strategies to facilitate patient engagement while maintaining family harmony. Strong religiosity may require to conceptualize ACP as a value exploration process rather than a "planning for the future" conversation.

Abstract number: N-20
Abstract type: Poster

Exploring how Health Professionals Communicate to Patients about Palliative Care

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Health care professionals (HCP) are responsible for delivering health information in a clear and understandable way. Even though we did not find publications about words used by HCP that convey the reality of Palliative Care (PC), we know that some terms have a negative connotation and may act as a barrier to early patient referrals. This study intends to know the terms used by HCP when communicating about PC with the patient, to the extent that reflect and convey the concept of this care. Identify the terms that HCPs use to communicate about PC; Analyse and compare the terms used, according to variables.

- Design: Quantitative, descriptive, and exploratory study
- Research question: What terms do HCPs use to communicate about PC with patients?
- Data Collection: online questionnaire, November 2019.
- Non-probabilistic sample, random type (n=234).
- Subjects: Nurses, Physicians, Social Workers and Psychologists.
- Variables: Gender, Professional Category, Years of Experience, Expertise in PC and experience with relatives undergoing PC;
- Data analysis: SPSS (nº25), $p<0{,}05$.
- This study complied with the ethical norms and regulatory guidelines.

The five most used terms to convey the reality of PC are: Quality of life (40,4%); Comfort (38,3%); Symptomatic control (22,8%); Family (17,1%); Relief (16,6%). The term most mentioned by nurses was "Comfort" (32,3%) and the other HCPs chose "Quality of life". Professionals who have never worked in PC usually associate the term "Respect" (p=0,036). Although there were no statistically significant differences between the terms and the variables, results reveal a change in mentalities as all the words stand out as having a positive connotation. It is necessary to maintain investment in communication and literacy about PC, with the aim to improve knowledge and access to services, to best prepare HCPs, have communities more engaged and, finally, achieving the objectives reflected in the international consensus.

Abstract number: N-21
Abstract type: Poster

Asian Patient's Willingness to Engage in Advance Care Planning: A Mixed-method Systematic Review and Conceptual Framework

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Background: Family has an essential role in advance care planning (ACP) in Asia. Little is known about patients' views on engagement in ACP.

Aim: To understand Asian patients' perspectives towards and willingness to engage in ACP and the underlying reasons.

Methods: We systematically searched English literature in EMBASE, MEDLINE, Web of Science, and Google Scholar from inception to July 27*th*, 2020. Two reviewers independently screened and assessed the quality of studies from southern, eastern, and southeastern Asia reporting the perspectives of Asian patients with serious illness towards ACP, their willingness to engage in it and the underlying reasons. We employed a mixed-method systematic review by transforming quantitative to qualitative data and developed a conceptual framework.

Results: Of 7,118 articles searched, 36 were included, 22 were quantitative, and 27 were from high-income countries. Twenty-two to 80% of Asian patients supported the concept of AD. Essential preconditions for ACP engagement are sufficient knowledge of their disease and of what ACP entails. Willingness to engage in ACP is affected by various beliefs: beliefs towards the consequences of ACP; beliefs about the conformity of ACP with patients' faith and families' or physicians' wishes; and beliefs about the presence of barriers for engagement in ACP (complexities of planning for the unknown, patients' socioeconomic dependence, unskilled physicians, unprepared system). Important considerations for engagement in ACP include patients' preference of role in ACP (active engagement versus extending autonomy to their family or physicians), the best timing to initiate ACP conversations, and the formality of ACP (whether or not the discussion is documented).

Conclusion: Educating patients about their diseases and ACP is an essential first step to engage patients in ACP. In the Asian context, ACP should accommodate patients' diverse beliefs on ACP and preferences for role, timing, and formality.

Abstract number: N-22
Abstract type: Poster

Empowering People with Bone Metastases to Stay Active to Improve their Quality of Life

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Aim: Exercise can play an important role in improving quality of life and maximising physical abilities in people with bone metastases. However, such patients are often unsure if exercise is suitable and how to do it safely. Also, despite evidence supporting the safety of exercise in this group, healthcare professionals (HCPs) can be unsure what exercise advice is suitable and reluctant to prescribe it due to concerns about increased risk of fracture.

Approach taken: To communicate the benefits and safe incorporation of exercise into daily life for people with bone metastases, a free, live, 1-hour webinar was developed. The structure and promotion of the webinar was guided by the knowledge transfer and exchange model – EMTReK. Multiple email distribution lists, social media platforms and websites were used to invite patients, carers, and HCPs to attend. The webinar, delivered by two registered physiotherapists, used plain English and relatable imagery to communicate the literature in a meaningful and manageable way. To mitigate risk patients were advised to be 'as active as comfortable' and speak to their medical team if experiencing new pain. To meet HCPs' needs reference lists were provided. Attendees had an opportunity to ask questions. Post-event the webinar recording and slides where distributed widely through social media platforms, public and professional websites and with registrants.

Results: Quantitative data and informal feedback (Table 1) were aggregated and analysed.

Table 1.

Registration & Attendance Records:
People registered 477
People who attended 319
Views of Webinar Recording Post Event* 326
Attendance Breakdown:
Public attendance 141
Professional attendance 178
Countries in attendance 16
Sample of feedback from persons with bone metastases:
'Was very informative for me. . .'
'. . .I found it very informative and helpful'
Sample of feedback from health care professionals:
'. . .very useful and always good to know what language to use and level to pitch discussions with patients. . .'
'. . .appreciate the much needed information and training. . .'
'. . .excellent information session. . .'
**[YouTube views recorded 23/02/2021]*

Conclusion: The positive engagement with the webinar demonstrates patients' and HCPs' interest in physical activity and bone metastases. It also highlights how researchers can facilitate communicating specialised research knowledge (beyond readers of scientific journals) in a credible and meaningful way through multiple communication channels to inform and empower patients and support HCPs to use evidence-based knowledge.

Abstract number: N-23
Abstract type: Poster

A Scoping Review on Advance Care Planning in Neurological Chronic Diseases

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Background: Neurological chronic diseases are incurable, associated with increasing disability, and reduced life expectancy. Therefore, advance care planning (ACP) is increasingly acknowledged as a key step to enable individuals to define goals and preferences for future medical care, and discuss these goals and preferences with family and health professionals (HPs).

Aims: To summarize the available evidence on ACP in neurological chronic diseases.

Methods: We performed a scoping review using the Arksey & O'Malley framework. We searched Pubmed from inception to December 28, 2020. Trial, review, and dissertation registers were also searched for published/unpublished studies. We included primary/secondary research focused on ACP in neurological chronic diseases related to patients, carers, HPs, or combination.

Results: From 9367 records, we included 55 studies, mostly conducted in Europe (43%) and US-Canada (41%), and within the last 5 years. 27% of studies were qualitative, followed by reviews (20%), observational (18%), randomized controlled trials (RCTs, 18%), quasi-experimental (11%), and mixed-methods (5%). 67% of studies were conducted in dementia, followed by amyotrophic lateral sclerosis (13%), brain tumors (9%), Parkinson's disease (4%), mixed populations (4%), Duchenne muscular dystrophy (2%), and multiple sclerosis (2%). 24% of studies addressed patients, HPs (16%), carers (15%), or a combination (45%). All the RCTs were conducted in dementia. Of those, intervention components differed across studies with majority including facilitated discussions/educational programs.

Conclusions: Geographical distribution of studies is in line with the recent general literature on ACP. Most studies were performed in dementia, with RCTs only in such a disease. Importantly, no study was conducted in secondary and atypical parkinsonisms, and Huntington's Chorea. More research is needed using rigorous design, and in almost all the chronic neurological diseases, except dementia.

Abstract number: N-24
Abstract type: Poster

Teaching and Assessing Communication Skills in Palliative Medicine: A Systematic Scoping Review

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Poor communication skills can compromise patient care in palliative medicine. As accreditation bodies have only called for mandatory communication skills trainings (CSTs) in recent years, CSTs are new to most hospital departments. This systematic scoping review aims to gather data on existing CSTs to identify key factors in teaching and assessing communication skills in the palliative care setting so that effective evidence-based CSTs applicable to the post-COVID-19 era can be designed.

Independent searches across 7 bibliographic databases were carried out. A 'split approach' comprising thematic analysis, directed content analysis and tabulated summaries of included articles was employed.

25,809 abstracts were identified, and 109 articles were included and analysed. Themes revealed include problems with existing CSTs; guiding principles for curriculum design; teaching methods; curriculum content; assessment methods and outcomes measured; integration of curriculum; and resources, facilitators and barriers to effective training.

A major flaw in existing CSTs is the lack of curriculum structure, focus and standardisation. The planning and execution of a CST curriculum needs to be stepwise and competency based. Holistic assessment by faculty, simulated patients and peers on the learner's performance plays a key role in consolidating knowledge. The educational institute must clearly define the objectives of the programme, allocate sufficient administrative and financial resources, and ensure the wellbeing of its stakeholders.

Beyond medical education, a spiral curriculum with longitudinal assessments will equip learners in palliative care with the necessary skills and confidence to face complex communication scenarios in our healthcare landscape. Good communication skills can improve patient satisfaction, treatment compliance, and reduce physician burnout and the frequency of malpractice claims. This strengthens the overall doctor-patient relationship in palliative care.

Abstract number: N-25
Abstract type: Poster

Nurse-physician Communication around Identifying Palliative Care Needs in Nursing Home Residents

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Background: To provide palliative care for nursing home residents, local multidisciplinary teams must communicate about observed changing care needs, which may be physical, psychological, social or spiritual needs.

Aims: To assess on-staff physicians' experiences with communication with nursing staff about identifying emerging and changing (palliative) care needs of nursing homes residents.

Methods: Qualitative study using semi-structured individual interviews with 15 physicians and 2 nurse practitioners employed by 8 care organizations in an urbanized region of the Netherlands in 2018. The topic list was informed by a qualitative dataset on barriers and facilitators to palliative care in dementia reported by elderly care physicians. The interviews were recorded, transcribed verbatim and analysed with Atlas.ti. We used both deductive and inductive coding adding refined codes related to communication.

Results: All interviewees expressed appreciation for nursing staff but also reported a variety of communication challenges around important changes in resident's condition which were covered by two themes.

(1) Teamwork was facilitated or impeded by team size and structure, quality of relationships and clarity in hierarchical relationships.
(2) Continuity of information was affected by (in)effective routes of consultation and (lack of) detail in communicating observations.

Discussion: Also in the case of on-site physicians, functioning of the multidisciplinary team and accurate sharing of observed changes in nursing home residents' condition are crucial for physicians to be able to address palliative care needs. The physicians' expressions of how they would favor nursing staff to communicate can inspire interprofessional training, such as reporting objective observations, and phrasing a clear request for help while avoiding overly demanding appeals.

Funding: ZonMw The Netherlands Organisation for Health Research and Development.

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Abstract number: N-26
Abstract type: Poster

Does the AMBER Care Bundle Have a Role in a Regional Cancer Centre?

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Background: The AMBER Care Bundle (ACB) is a nationally available tool to enhance communication and support for patients with uncertain recovery and facilitate early discussions with patients and those important to them about what their preferences may be if their condition does not improve. Previous attempts to embed this tool at our centre have failed due to lack of education and a perceived lack of appropriateness of this tool in a tertiary cancer setting.

Aim: To establish clinical need and possible strategies for establishing the ACB at our centre.

Method: A retrospective audit of patient's case notes from patients who had died between February and June 2020 was undertaken to establish whether there was a recognition of uncertain recovery in acutely unwell patients at out centre without the ACB. Data was collected regarding whether proactive conversations were had with these patients and whether treatment escalation discussions were had at the point that uncertain recovery was recognized.

Results: 40 patients' case notes were sampled, representing 20% of the total cohort. 36 (90%) had an acute deterioration judged to be suitable for the ACB if available. 25 (63%) of patients had a discussion with the team about the fact that they may not recover. For 21/25 this included a treatment escalation plan and in 15/25 this included a resuscitation discussion. 50% of patients died during that admission and the other 50% died within 100 days of discharge but 21 (53%) were not asked about a preferred place of care despite their acute deterioration during their hospital admission.

Conclusion: The ACB has a role within our centre in guiding discussions when patients deteriorate acutely and recovery is uncertain. Whilst willingness to communicate with patients and families about uncertain recovery is generally good, the content of that discussion requires some structure and guidance, facilitated by the ACB, to enable patients' wishes to be respected if they do not recover.

Abstract number: N-27
Abstract type: Poster

Communicated Values, Wishes and Needs of Hospitalized Patients and their Loved Ones: A Survey among Clinicians

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Background: In palliative care, person-centered care based on patients' values, wishes and needs is perceived as optimal care. However, challenging to perform by clinicians in daily practice.

Aim: To map the current situation, facilitators and barriers regarding the exploration and monitoring of values, wishes and needs of hospitalized patients with life-threatening conditions and loved ones perceived by clinicians.

Methods: An explorative cross-sectional survey is conducted using a convenience sample of hospital clinicians. Doctors and nurses of eight wards in two tertiary and two secondary hospitals in the Netherlands were invited to participate. The survey was developed based on literature and previous studies and tested on face validity and feasibility by clinical experts. Data was analyzed using descriptive statistics.

Results: Preliminary results of two wards showed that all participants (N=50) were able to discuss the patients' values, wishes and needs. For 35%, the patients' values, wishes and needs were not or not structurally discussed or information was obtained from other team members. Values, wishes and needs were mostly discussed on the patient's initiative, in recognizing and responding to emotions or during decision-making about treatment. Conversations mainly focused on symptoms related to the physical (80%) and psychological (51%) dimensions. The social

(33%) and spiritual (31%) dimensions were less explored. The care that loved ones provide and related wishes and needs seemed to be overlooked. Lack of time and differences in cultural background were perceived as most important barriers.
Conclusion: Development and implementation of a structured approach enhances dedicated attention for improving person-centered communication with hospitalized patients with life-threatening conditions and their loved ones to achieve a multidimensional approach and to involve loved ones in exploring their wishes and needs.
Funding: Jonker-Driessen Foundation

Abstract number: N-28
Abstract type: Poster

Identifying the Most Important Behavioral Determinants of Starting a Conversation about Palliative Care with the Physician: A Cross-sectional Structured Interview Study on People with Cancer

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Background: Lack of palliative care (PC) communication can lead to suboptimal care in the final months of life. Insight into if and how patients speak to their physician about PC is needed and might improve patient empowerment and timely initiation of PC.
Aim: To assess which determinants are (most strongly) associated with having started or intending to start a conversation about PC with the physician in people with cancer.
Methods: We performed a cross-sectional survey with computer-assisted personal interviews among 88 people with incurable cancer. Purposive sampling taking into account the theoretically important heterogeneity was used. The questionnaire was based on an extension of the theory of planned behavior and included following determinants: knowledge, attitude, perceived behavioral control, subjective norm and social influence. Uni- and multivariable logistic regression analyses were performed.
Results: Ten participants started a conversation about PC themselves, 19 had the intention to do so. Fifty-nine did not start the conversation and had no intention. Holding a more positive attitude towards the behavior (OR 4.26; 95%CI 2.23-8.13), perceiving more benefits (OR 2.66; 95%CI 1.40-5.07), perceiving a higher behavioral control (OR 1.94; 95%CI 0.99-3.80) and perceiving a positive attitude towards the behavior in family/friends (OR 2.07; 95%CI 1.26-3.41) and the physician (OR 2.19; 95%CI 1.39-3.45) were positively associated; perceiving more disadvantages (OR 0.53; 95%CI 0.32-0.87) and barriers (OR 0.31; 95% CI 0.15-0.63) were negatively associated with performing or intending the behavior. These factors explained 64% of the variance (Nagelkerke R^2).
Conclusion: This study suggests that particularly attitudinal determinants influence initiating a conversation about PC with the physician. Interventions targeting these determinants, can help empower people with cancer in taking the initiative in communication about PC.

Abstract number: N-29
Abstract type: Poster

Prognostic Decision-making within Multidisciplinary Teams: A Scoping Review

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Background: Clinicians' predictions of survival are often inaccurate. However, a slight improvement in accuracy is found after a multidisciplinary team (MDT) discussion. How MDTs make prognostic decisions about whether a patient is imminently dying, needs further examination.
Aim: To summarise the evidence on how MDTs make decisions about the identification of imminently dying patients.
Method: A scoping review was conducted using a narrative synthesis approach. AMED, CINAHL, Embase, MEDLINE, PsychINFO and Web of Science were searched from inception to April 2020. Included studies presented original data, were written in English and reported the process or content of MDT discussions about identifying imminently dying adult patients.
Results: 22 studies were included in the review. The majority of studies used qualitative methods of data collection (e.g. interviews) and analysis (e.g. thematic analysis). MDT members involved in decision-making were usually doctors and nurses. Allied healthcare professionals were involved less frequently. Identifying dying was often addressed when clinicians discussed other issues (e.g. care goals). Prognostic decision-making was often not the main study focus and therefore not fully reported. There was varied evidence for how MDTs make such decisions; ranging from no collaboration (i.e. a team member made the decision without input from others) through to full collaboration (i.e. the MDT shared information and made a joint decision). Other reoccurring themes included disagreement between team members and doctors being described as sole decision makers.
Conclusion: Future research should focus explicitly on MDT prognostication using quantitative methods or methods that investigate MDT interaction. Research that includes allied healthcare professionals and investigates their role in MDT prognostication is needed. A focus on specialist palliative care settings is also necessary.
Funding: PhD Studentship, Marie Curie Chair (ref: 509537).

Abstract number: N-30
Abstract type: Poster

Information Needs about Palliative Care in Patients with a Life-threatening Illness and Their Relatives. Results of a Mixed-method Study in the Netherlands

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Background: An aging population combined with people living longer with comorbidity means that more and more people have palliative care needs. Which specific information about palliative care patients and relatives wish for, is not well known.
Aim: The aim of this research is to get insight into the information needs of people with a life-threatening illness and their relatives, and their preferences for ways of presenting this information.
Design, methods and approach taken: We used a cross sectional, mixed-method study design, including a questionnaire and interviews. Respondents were recruited via the healthcare panel of The Netherlands Patients Federation and the Lung Foundation Netherlands.

Results: In total, 650 people completed the questionnaire, including 112 patients with a life-threatening illness and 538 relatives. Their median age was 65.

70% of the patients had questions about palliative care. Most people seem to think about end of life care when they are asked about palliative care. 39% prefers to receive information in a personal conversation with their healthcare professional. Patients and relatives have similar questions; both are looking for information on what is going to happen in the future and organization of care. 25% wants to be able to visit a website which only contains information on palliative care, and 10 % wants a peer forum.

Most mentioned topics were, palliative sedation, euthanasia, information for surviving relatives, process of dying and physical symptoms (e.g. pain, fatigue, nausea). Relatives have questions on what they can do to ensure that their loved one suffers as little as possible in the process of dying.

Conclusion: Many patients and relatives have questions about palliative care. Oral information from healthcare professionals is very important. Online information is seen as an addition and not a substitute. People want information which is understandable, short, reliable and targeted on their specific situation.

Abstract number: N-31
Abstract type: Poster

Decision Making in the End-of-Life Care of Cancer Patients: A Qualitative Descriptive Study from the Experience of Colombian Healthcare Workers

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Background: In Colombia, legislation regarding end-of-life (EoL) decisions includes palliative sedation, advance directives and euthanasia, little is known regarding the decision-making process.

Aims: To analyse which aspects influencing health professionals' decisions and opinions regarding EoL of cancer patients in Colombia.

Methods: Qualitative study using semi-structured interviews with 28 health professionals involved in EoL care of cancer patients in 3 Colombian institutions.

Results: In EoL decision-making, professionals consider: 1. Patient's clinical, cultural and social context, in particular treating indigenous patients requires special skills. 2. Professional conditions: training in palliative care and experience EoL conversations, fear of legal consequences. Physicians feel that many patients deny their imminent death which hampers shared decision-making and conversations. There is a lack of clarity regarding who initiates conversations regarding EoL preferences with patients and who finally takes decisions. Patients rarely initiate such conversations; the professionals normally do not ask patients' preferences. Fear of confrontation with family members and lawsuits lead to execution of interventions, even in absence of expected benefits. Acceptance of palliative sedation and euthanasia vary greatly. 3. Conditions of the insurance system: there is limited offer of oncology and palliative care services for important parts of the Colombian population. There is access to opioids, barriers are in delivery by the health system, requirements of trained personnel for intravenous administration and relative absence of ambulatory and home care plans.

Conclusion: To improve EoL decision making, improved conversation skills of physicians regarding wishes and needs are needed. Development of palliative care centres and home care could facilitate access to EoL care. Patients and caregivers' perspectives are needed to complement physicians' perceptions and practices.

Abstract number: N-32
Abstract type: Poster

Communication Is Not Just Words

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Background: Communication, often through verbal conversations, is a fundamental part of the care of seriously ill patients. The conversations often take place between healthcare professionals' and the patient and/or their loved ones. Staff can control the information provided but do not know how it is passed on by the patient and loved ones. The purpose of the study was to increase the understanding of what it is like for the patient to tell others (family, friends, networks) about experienced difficult messages they have received. By examining how the information is passed on by the patient to loved ones, knowledge about the processes that take place between patient and loved ones can increase.

Method: The study has a qualitative design with in-depth interviews with patients and their loved ones. The interviews were recorded and written verbatim. Qualitative content analysis was applied.

Result: 15 patients and 7 loved ones were interviewed. The results showed that both patients and loved ones choose who to tell and what to tell. The information in the conversation can contain both facts and feelings, depending on what is convenient for the narrator. Especially at the time of diagnosis, the information is more focused on practical information regarding treatment and practical consequences. Emotions are used by those who feel comfortable expressing them. Information is also conveyed regarding how the disease affects the body, what the disease process entails in daily life and what aids are used.

Conclusion: Verbal information can be clear when it is conveyed, although the patient chooses what words to use. However, information is also conveyed by other means than words. Loved ones are aware of the silent information given by changes in the patient's body as well as in his/her daily life. It is important that healthcare professionals are aware of the different parts of the communication and have an understanding of how patient's and loved one's communication works.

Abstract number: N-33
Abstract type: Poster

The SHIPS Study: SHaring Information at the Primary/Secondary Care Interface for Patients with a Poor Prognosis

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Background: Up to one in three people die in the 12 months following an emergency hospital admission and this is an opportunity for hospital clinicians to identify patients with a poor prognosis and share this with General Practitioners (GPs). There is a lack of consensus about this communication and a need to synthesise the evidence in order to improve continuity of care.

Aims: To investigate the communication of poor prognosis from secondary care to primary care at hospital discharge.

Methods: The study will be conducted in two phases:

1. A systematic review with narrative synthesis of evidence on sharing information about patients with a poor prognosis between secondary care and primary care. The review will address the following questions: How is poor prognosis communicated? What are the facilitators of, and barriers to, this communication? What evidence exists of the impact of this communication on patient care? How acceptable and useful is this communication to patients, family/carers and clinicians?
2. A focused ethnography to explore the communication of poor prognosis to GPs on discharge from hospital. Data collection will take place in four hospital trusts and linked GP surgeries in two regions in England. Non-participant observation will be conducted on 12 hospital wards across the four trusts, to explore decision-making around the sharing of prognostic information with GPs at discharge and the facilitators of, and barriers to, sharing this information. Anonymised examples of written information sharing will be collated alongside documentation of telephone calls with GPs in the medical records. In-depth interviews will be conducted with purposive samples of hospital clinicians, GPs, patients and carers about the process of information-sharing and their views of this.

Results and conclusions: The results of the phase one systematic review will be available for presentation at the time of the conference.

Abstract number: N-35
Abstract type: Posters

Prognostic Awareness in Terminal Cancer Patients: A Secondary Data Analysis of IMPAC Study

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Background: Prognostic awareness (PA) relates to patients' capacity to understand the terminal nature of the disease. Previous studies showed that around 25 % of patients with advanced cancer are usually completely aware of their prognosis which is associated with worse quality of life (QoL).

Aims: The aim of this study was to compare PA of patients at the end of life with PA of patients with advanced cancer who had better survival.

Methods: IMPAC was a multicentre longitudinal cohort study (data were collected during 9 months in 3 waves) in patients with advanced cancer (assessed by 12-months surprise question). PA was measured by: Terminal Illness Acknowledgment Tool, a question about goals of treatment and estimation of patients' chance to be cured using a percentage scale. QoL was assessed using IPOS. Secondary data analysis was conducted on a subsample of patients who died during the study. Differences in PA were assessed using Cramer's V and associations with QoL were tested with ANOVA.

Results: 134 patients were recruited and 62 died during the study. On their last measurement, 24 % of patients who died later in the study were completely aware of their prognosis compared to 11 % of aware patients who did not die during the study. The differences in PA in these two groups were not significantly different at baseline (p= 0.06) and the second measurement (p= 0.15) and the third measurement (p= 0.62). Worse QoL was significantly associated with accurate PA in the sample (p= 0.02) but not associated with PA in the subgroup of terminal patients (p= 0.278).

Conclusion / Discussion: PA seems to be a stable concept but it might slightly change toward death. Accurate PA was not associated with worse QoL in terminal patients. The association between PA and QoL might be also explained by the worsened physical condition and therefore clinicians might not be afraid of prognostic disclosure.

This study was funded by the Czech Science Foundation grant No. 17-26722Y.

O Posters Bereavement

Abstract number: O-01
Abstract type: Poster

Predictors of Complicated Grief after Death of Relative due to Covid-19

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Background: Currently in Italy there are 91.273 Covid-19 related deaths. The pandemic changed the way people die and how family members perceive patients' experience of illness and death. Qualitative studies showed that the caregivers of those who died for Covid-19 may have a high probability to develop prolonged grief disorder.

Aims: The present research aimed to investigate the associated factors of complicated bereavement, six months after the death of a relative due to Covid-19.

Methods: The participants were identified among the caregivers of Covid-19 patients admitted to hospital. A psychologist administered a set of validated rating scales assessing depression, anxiety and stress, complicated grief, relationship, perceived social support.The Mann-Whitney, Student's t test, Chi-square and Fisher's exact tests and Univariate logistic regression analyses were used.

Results: Caregivers were contacted to participate to the study; 31 completed the survey (51%). Complicated grief was present in 15 (48.4%) subjects. No significant association was observed between the presence of complicated grief and the relational attachment style, anxiety and stress levels. The protective factors seem to be represented by the opportunity to attend the funeral (p=0.007) and by perceived social support (p=0.027). Being single or widowed had a significantly higher risk to develop a complicated grief than married people or people that live with someone. The perceived sense of guilt was found significantly associated with the presence of complicated grief.

Conclusion: These data showed that having a greater depression level, being alone was associated to experiencing a complicated grief and highlighted the need to implement specific psychotherapies aimed to dealing with pathological bereavement of patients who died for Covid-19.

Abstract number: O-03
Abstract type: Poster

End of Life Experiences during the COVID-19 Pandemic: Results of a National Survey of Bereaved People

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Background: From March 2020-March 2021 530,000+ people have died from COVID-19 in the EU, and 120,000+ in the UK. In addition, c.4.85 million in the region have died of other causes, leaving c.43.6 million people bereaved at a time of unprecedented social and clinical restrictions. We aimed to inform practice and policy by describing end of life experiences among people bereaved during the pandemic.
Methods: National survey of people bereaved in the UK since March 2020, disseminated via media, social media, national associations, community/charitable organisations.
Results: Interim findings from the first 532 participants are reported (full results available by time of conference). 55% of deaths were in hospital; 46% were caused by confirmed/suspected COVID-19. Respondents reported high levels of problems specific to the pandemic bereavement context: 56% were unable to visit their loved one prior to death, 59% had limited contact in last days of life, 67% were unable to say goodbye, 67% experienced social isolation and loneliness, 81% had limited contact with other relatives/friends. COVID-19 deaths were associated with higher levels of all these problems compared with other causes of death (all $p < 0.05$). Experiences of end of life care were variable: 23% were 'never' involved in decisions about their loved one's care, 17% were not at all informed about the approaching death, 36% felt not at all supported by healthcare professionals after the death, 51% were not provided with information about bereavement support.
Conclusions: There is evidence of poor end of life care and challenging experiences among people bereaved during the pandemic. To reduce the trauma of negative death experiences, we recommend improved communication by healthcare professionals, with a known point and method of contact, family involvement in decision-making, enabling family visiting as far as possible, and better support after a death, including information about bereavement services.

Abstract number: O-04
Abstract type: Poster

Supporting the Bereaved Following Mass Bereavement Events: A Systematic Review of Disaster Response Interventions with Lessons for COVID-19

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Background: The COVID-19 pandemic represents a global mass bereavement event, on a scale seldom witnessed. National health and social care systems are challenged with supporting large numbers of bereaved people whilst also negotiating the ongoing restrictions to provide this support safely. This review aimed to synthesise the evidence regarding system-level responses to mass bereavement events, including natural and human-made disasters, to inform service provision and policy during the pandemic.
Methods: A rapid systematic review was conducted in April 2020, with narrative synthesis of results. MEDLINE, Global Health, PsycINFO and Scopus databases were searched for studies published between 2000 and 2020, reporting evidence on system-level responses to mass bereavement events in OECD countries (plus Singapore, China and Taiwan). Citation and reference tracking was conducted and study quality assessed.
Results: Six studies were included, reporting on system responses to man-made disasters (e.g. terror attacks in the US and Norway), as well as natural disasters (e.g. Hurricane Katrina and the South-East Asian Tsunami). Despite differences across disaster types, common approaches were identified and positive impacts were reported across a range of individual and group-based support interventions. Key features of service delivery included: a proactive outreach approach, centrally organised but locally delivered interventions, event-specific professional competencies and an emphasis on psycho-educational content. However, study quality was generally low and reliant on data from retrospective evaluation designs.
Conclusion: Co-ordinated responses to bereavement support which include the features we identified are required to meet the needs of bereaved people during and beyond the pandemic. Rigorous primary studies investigating the experiences of the bereaved and the services that support them are essential to inform current and future disaster response efforts.

Abstract number: O-05
Abstract type: Poster

How do Funeral Practices Impact Bereaved Relatives' Mental Health, Grief and Bereavement? A Mixed Methods Review with Implications for COVID-19

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Background: Funerals are a fundamental component of cultural and religious mourning systems that facilitate the offering of support to the bereaved. Those who are bereaved during the COVID-19 pandemic are subject to restrictions on funeral sizes and practices. It is possible that being unable to participate in funerals, rituals, and ceremonies will have a detrimental effect on the bereaved, affecting their mental health and ability to cope with or process their grief.
Aim: To synthesize evidence on the impact of funeral practices on bereaved friends and relatives' mental health and experience of bereavement, and consider implications for the COVID-19 pandemic.
Methods: We conducted a rapid systematic review according to PRISMA guidelines, synthesising the quantitative and qualitative evidence regarding the effect of funeral practices on bereaved relatives' mental health and bereavement outcomes. Searches of MEDLINE, PsycINFO, KSR Evidence, and COVID-related resources were conducted on 24/4/2020.
Results: 805 records were screened; 17 studies of variable quality were included. Current evidence regarding the effect of funeral practices on bereaved relatives' mental health and bereavement outcomes is inconclusive. Five observational studies found benefits from funeral participation while six did not. However, qualitative research provides additional insight: the benefit of after-death rituals including funerals depends on the ability of the bereaved to shape those rituals and say goodbye in a way which is meaningful for them, and on whether the funeral demonstrates social support for the bereaved.
Discussion: Our findings suggest that restrictions to funeral practices do not necessarily entail poor outcomes or experiences for bereaved people. As well as access to bereavement support and sign-posting to specialist services, palliative care and bereavement teams should provide locally-relevant information regarding the creation of meaningful, culturally appropriate funerals.

Abstract number: O-06
Abstract type: Poster

Accuracy of Bereavement Risk Assessment in Palliative Care: A Pilot Study

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The bereavement risk assessment is a regular practice in palliative care aiming to prevent the grief complications and ensure the continuity of support for the relatives who are most vulnerable. Accordingly, the national General Directorate of Health standard No. 003/2019 proposes a systematic risk assessment using hetero-evaluation tools. In this study, we aim to verify the accuracy of this assessment method in identifying individuals in need of grief support. A prospective cohort study was conducted with relatives followed in PC. Participants were hetero-evaluated during end-of-life caregiving using the Risk factors checklist. One month after the patient's death, they were approached by telephone to apply the Instrument of Risk in Bereavement. On the follow-up, they were asked for self-reported perceived difficulty in adjustment to bereavement. Additionally, the total number of psychology consultations was computed as an objective measure of adherence to grief therapy. The sample includes 77 participants, mostly relatives of cancer patients. The majority were women (84.4%), spouses (50.6%) or adult children (40.3%) of the patient, with an average age of 56.13 (SD = 13.36). The results showed that the bereavement risk assessment instrument was predictive of the perceived difficulty in adjustment to bereavement (r^2=.325, $p<.001$). Factors significantly correlated with greater difficulty in adjustment to bereavement were: the avoidant coping, maladaptive spiritual coping, inability to find meaning in the loss and the lack of preparation for death. People classified as at high-risk perceived less socio-family support and showed more adherence to grief consultations, reflected in longer grief therapy accompaniments. These findings confirm the accuracy of the evaluation process in identifying the people who most need support in bereavement, so it is recommended the generalization of this practice to all the PC services for systematic bereavement risk assessment.

Abstract number: O-07
Abstract type: Poster

Interventions for Grieving and Bereaved Informal Caregivers: Results from A Scoping Review of the Canadian Literature

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Background: Informal caregivers are a significant part of Canada's hospice palliative care landscape as members of the interdisciplinary care team. Although there are interventions that aim to support them through the grief and bereavement process, there is a paucity of research that provides an overview of the existing interventions.
Aims: The objective of this scoping review was to examine the types of grief and bereavement interventions geared toward informal caregivers that exist in Canada.
Methods: A scoping review of the literature was conducted following Arksey and O'Malley's 5 step framework. Key electronic healthcare and social sciences databases (e.g., CINAHL, ProQuest Sociological Abstracts, PsycINFO, MEDLINE) along with the grey literature were searched. Relevant sources were screened for inclusion criteria and a thematic content analysis was employed to summarize key findings.
Results: 15,000 initial records were generated and 30 sources marked for inclusion. Preliminary themes that emerged were: timing of the intervention (pre-death or post-death), format (e.g., one-on-one counselling, group therapy, or music therapy), and type of delivery (e.g., telephone, in-person or online). Each of these factors contributed to the uptake of bereavement services for informal caregivers in Canada.
Conclusions: This knowledge will ultimately help to inform and to improve upon current research, policy and practice to enhance grief and bereavement supports for informal caregivers in Canada and beyond. Additional research should delve further into the understudied interventions identified by this review, and investigate the efficacy of these interventions in terms of health outcomes.

Abstract number: O-08
Abstract type: Poster

Exploring the Grief and Bereavement Experiences of Informal Caregivers in North America: A Scoping Review of the Literature

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Background: Informal caregivers are a significant part of Canada's hospice palliative care landscape at all times. Despite this, little is known about the impact this responsibility has on informal caregivers' experiences of grief and bereavement.
Aims: This scoping review aimed to explore the grief and bereavement experiences of informal caregivers of geriatric patients in North America. Addressing this knowledge gap will help to inform research, practice and policy.
Methods: Following Arksey and O'Malley's 5-step framework, key electronic healthcare and social sciences databases (e.g., CINAHL, ProQuest Sociological Abstracts, PsycINFO, MEDLINE) alongside grey literature sources were searched and screened against inclusion and exclusion criteria. A thematic content analysis was used to identify key themes.
Results: 29 articles met final inclusion criteria, with three central themes emerging:

(1) mediators of grief,
(2) grief experiences, and
(3) types of grief.

Discussion: This review identified that informal caregivers encounter unique grief and bereavement experiences. The range of psychosocial outcomes, both negative and positive, and types of grief faced by these caregivers can be affected by various mediators such as caregiver burden, demographics, disease type of the patient being cared for, etc. Thus, bereavement interventions should be designed with mediators of grief in mind to allow for earlier and appropriate support.
Conclusions: Understanding the nuances of informal caregivers' experiences with grief and bereavement will inform and advance practice, policy and research. Further research is needed to solidify our understanding of informal caregiver grief experiences in the hospice palliative care setting in Canada and beyond.
Funding: None.

Abstract number: O-09
Abstract type: Poster

Quality Improvement Project: Bereavement Follow-up in an Acute Hospital during Covid-19 and beyond

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Background: Bereavement support is an important facet of palliative medicine. Many patients who receive end of life care in our hospital are not known to the hospice or hospital social workers. As a result, their families and carers do not avail of bereavement follow-up. This is particularly relevant as Covid-19 restrictions have interrupted the traditional community orientated bereavement process.
Aim and objectives: The goal is to quantify this cohort and facilitate a collaborative MDT quality improvement approach to acknowledge and address bereavement follow-up in the context of Covid-19 and beyond.
Methods: We quantified the weekly average number of families or carers who would not avail of bereavement follow-up prior to and during the Covid-19 surge. We reviewed the advice regarding bereavement support as per the Irish National Clinical Program for Palliative care 2018. The palliative team discussed this service gap with different stakeholders including the hospice, cancer care west, medical social work and the bereavement officer. A number of quality improvement methods were employed; such as stakeholder map, fishbone analysis, driver diagrams and the 5 whys.
Results: The average weekly number of families/carers who did not avail of bereavement follow-up prior to Covid-19 was 3 and during the Covid-19 surge was 10. Quality improvement methodologies revealed that the gap in bereavement follow-up was due to a lack of a palliative care social worker. To address this gap short-term a bereavement information leaflet was designed which will promote self-recognition of prolonged grief and signpost options available for support.
Conclusion: Bereavement support is an important component of palliative care, which is often lacking. This project utilised a multidisciplinary quality improvement approach to improve this service gap with a bereavement information leaflet in the short-term and a long-term plan aimed at funding a palliative care social worker.

P Posters Volunteering

Abstract number: P-01
Abstract type: Poster

Understanding volunteer work in palliative care in Nordic countries - A systematic review of qualitative studies

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Background: Volunteers are integrated into the provision of palliative care in many countries, but research-based knowledge of what characterizes the volunteer practice in palliative care in Nordic countries is lacking.
Aim: To identify and summarize qualitative studies describing experiences the volunteer practice in relation to people with palliative needs in a Nordic healthcare context.
Methods: In accordance with PRISMA guidelines we undertook a systematic review in the following databases from Dec. 7th until Dec. 31th 2020: CINAHL, APA PsycINFO, SocIndex, Danish Research Database, Idunn, Christin, SwePub, SweMed+, and DORIA based on keywords in PICo search strings. We used thematic synthesis of study findings. Mendeley collaboration platform was used in storage and division of citations and Covidence software structured and blinded the screening process.
Inclusion criteria: Peer-reviewed qualitative studies published between 2005-2020 providing firsthand experiences of volunteer practice in relation to palliative care in Nordic Countries.
Results: Of 1321 citations 11 studies were eligible for review: 7 (NO), 3 (SE), and 1 (DK). Nine studies used data from community healthcare (NO, SE). Two studies provided data from hospice (DK, SE). The thematic analysis revealed three overall analytical themes of importance for understanding the role of the volunteer: *'Offering something that differs''*, *'Personal gains' and 'Challenges in volunteer-professional caregiver cooperation'*.
Conclusion: Volunteers in palliative care offer something that differs from what the professional caregiver can offer. Volunteers provide the patient with valuable fellowship and ease the burden of the patient's next-of-kin. To be a volunteer has personal gains, and volunteers' supplemental practice in healthcare in Nordic well-fare states also has organizational challenges and challenges in relation to volunteer-professional caregiver cooperation.

Abstract number: P-02
Abstract type: Poster

REVOL-Pal Project, Palliative Care Volunteer Network: "New Challenges, New Volunteers"

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Background: Social isolation in pandemics leads to difficulties in comprehensive palliative care for patients and families.
Aim: Create a network of 15 senior pc volunteers that provides face-to-face or telematic support to patients and family, with a more autonomous and proactive role.
Design, methods and approach: Volunteers, professionals and patient-family will participate in the design and evaluation of the project in each phase: *Design*: qualitative method with 2 focus groups for volunteers and professionals and in-depth interviews for patients/families (approx. 7 participants per group). Review project and integrate proposals by defining a version 1 of Senior Volunteers Training Programme. (1 month). *Training* 15 senior volunteers in communication and new technologies. Ad hoc surveys of satisfaction and knowledge acquired at the end of training -version2- (1 month). *Piloting* with 40 patients from 1 municipality: Ad hoc patient-family satisfaction survey, volunteers and professionals with monthly follow-up meetings for volunteers and professionals –version3- (3 months). *Implementation* in 7 municipalities: Quantum-qualitative method of emotional distress EVA of patient-family; monthly Zarit overload caregivers scale; monthly volunteer satisfaction scale; monthly ad hoc survey of patient/family volunteers, professionals with monthly follow-up meetings for volunteers and professionals (6 months).
Results: The continuous evaluation of the project will allow to identify improvements in activities, organization and resources, integrating them into the final version of the training programme for volunteers and in the design of the service extending the network to more municipalities.

Conclusions: The creation of a network of senior volunteers will help improve communication and ongoing patient-family care, mobilize local resources in coordination with social work and create bridges between patient-family and professionals facilitating their work detecting needs.

Abstract number: P-03
Abstract type: Poster

ITV-Pal Programme: Evaluation of the Implementation of Tech-volunteer Programme in Palliative Care Services

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Background: Due to COVID-19, team has piloted new service of volunteers supporting patients/relatives isolated home using telephone and videocalls, with global good response to this initiative. The literature review shows no robust studies associating palliative care (PC) volunteering with new technologies (NT).
Aims: The main goal is implementing and evaluating volunteer training programme in the use of NT (specifically smartphones and tablets) to support patients facing life-threatening illness and relatives. Specific objectives are:

1. Explore need and usefulness of NT from point of view of patients/relatives, volunteers and health care professionals (HCP) in PC and describe technological profile.
2. Design techvolunteer curriculum and implement techvolunteer training programme.
3. Implement techvolunteer programme within PC home care service and Inpatient unit and assess impact on care provided.

Methods: Pilot study: 20 volunteers and 70 patients/relatives.
Mix-methods design allows combining quantitative measures of implementation with in-depth qualitative data to provide detailed understanding intervention functioning on small scale.
Pragmatic cluster randomized clinical trial to test efficacy (unit of randomization is the volunteer and unit of analysis is patient/relative). Before-after design to test effectiveness (volunteers and HCP satisfaction with intervention and its implementation). Cost-utility study.
Interviews (individuals and groupal) with HPC, volunteers and key informants of patients/relatives to test the beginning need and usefulness of NT, and during implementation process to test changes and experiences.
Intention to treat analysis.
Conclusion: This study will bring real evidence toward NT integration as useful tool not only to facilitate communication between volunteers and patients/relatives, but also to turn NT into instruments support daily living and enhance care, when in the hands of trained tech-volunteers.

Abstract number: P-04
Abstract type: Poster

Summary Eapc Experimental Case - Implementation of a Volunteer Program through New Technologies to Palliative Patient: Pilot Study

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Background: Essential volunteers accompanying palliative patients and their family. New technologies (NTs) have become an important tool for social support during the pandemic.
Aim: Detect needs and positive aspects of a volunteer’s accompaniment to a palliative patient through NTs.
Design, methods and approach: Volunteer (V) with 7 years of experience in a Hospitalization Unit in palliative care to palliative patient (P) with the criteria of loneliness, poor social network, communicative and prolonged prognosis. Both agreed to two weekly telephone contacts from V to P. After each, the V would record: date and duration of the call, topics addressed in the conversation and needs detected in the P. The social worker (SC) and the medical team (MT) evaluated the P’s satisfaction with the V in their contacts. On the other hand, weekly telephone contacts were established with the V to track her performance and monthly virtual meetings to make an organizational assessment. The accompaniment began in December 2020 and continues today.
Results: So far, 10 scheduled contacts have been made from the V to the P with an average duration of 45 minutes. The main topics addressed were: general topics as politics, religion, current news and life story. 6 unscheduled contacts have also been established from the P to the V; In these cases, the topics addressed were healthy. The SC and the MT have twice contacted the V about healthty’s P. The volunteer department has maintained 12 follow-up contacts with her and 4 follow-up meetings with the SC.
Conclusions: The usefulness of the service and the need to design protocols adjusted to the situation of voluntary digital accompaniment between P and V have been observed. Clearly, NTs favour the creation of affective links and mutual assistance by overcoming mobility constraints and social distancing motivated by the current pandemic.

Abstract number: P-05
Abstract type: Poster

Don’t Know what You’ve Got (til It’s Gone) - Supporting and Sustaining Committed Palliative Care Volunteers

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Background: Palliative Care volunteers are positioned with unique knowledge and experience as a support for those at end-of-life, and are chosen for their maturity, empathy, and capacity for reflection. The suspension of palliative care volunteer services during the COVID-19 pandemic necessitated them being disconnected from their caring role in Palliative Care, and their supports in the Palliative Care sector. This offered an opportunity to explore issues related to volunteer commitment, support and retention.
Aim: To explore the experience of Volunteers during the COVID-19 pandemic, and their perceptions of connection, engagement and support from their local service.
Method: Volunteers from three services in two health districts were invited to complete an anonymous on-line qualitative survey six months after the cessation of services due to the COVID-19 pandemic. Data were collated using the Clinical Excellence Commission QARS platform and summary statistics prepared. A comparison of life satisfaction pre COVID and 6 months after service suspension employed McNemar’s Test.
Results: There were 53 responses (response rate of 50%). Overwhelmingly the volunteers indicated that their role added to their life satisfaction,

and not being able to volunteer had been a significant factor in its decrease. Over 80% of the volunteers indicated they intend to return to palliative care volunteering. The key themes identified were their relationships with patients and families, and being part of a team; and the giving/community service aspect of the role, as well as the connection with the volunteer manager.

Conclusion: Palliative Care volunteering is highly beneficial to volunteers themselves, as well as being an important community resource in the holistic care of those at the end-of-life. Managers of volunteers will best serve their volunteer program if they focus on the key themes identified in recruitment, training and ongoing support.

Q Posters Research Methodology and Methods

Abstract number: Q-03
Abstract type: Poster

Enrollment of Hematologic Cancer Patients in Palliative Care Research: A Realist-inspired Analysis of Data from Literature and Experts' Opinions

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Background: Research in PC is frequently challenging for many reasons, patient's frailty, study design, professional misconceptions and so on. In particular, little is known about specificity in PC research of Hematologic cancer patients who have distinct disease trajectories and characteristics that might influence the results of the enrollment process.

Aims: What works, how and for whom, in reaching an adequate enrollment in studies in hematologic PC?

Methods: Realist methods, through the retrieving of specific Context Mechanism Outcomes (CMO) configurations for hematologic patients. The theory was informed by literature research, interviews with expert in hematologic PC research and our own experience.

Results: In our initial theory we hypothesize that:

- access to palliative care could be beneficial to hematologic patients, even in early stages of serious diseases.
- hematologists tend to under-use palliative care services in general, due to unpredictable disease trajectories and cultural barriers.
- these factors may negatively impact the patients' enrollment, in projects aimed at delivering palliation.

We conducted a narrative, theory-based research of literature, searching for relevant, informing evidence resulting from research questions close to ours (consistently with realist methodology).

We found many plausibly relevant CMOs impacting enrollment in palliative care in other fields, and created a list of CMOs that could be relevant in hematology.

The interviews with prominent researchers in hematologic PC are ongoing, we ask for their opinion on our results, and additional CMOs.

Conclusions: Our final theory groups the various CMOs that might impact hematologic PC enrollments in main domains: the final results will be presented at the congress.

Abstract number: Q-04
Abstract type: Poster

Performance Status and Site-level Factors Are Associated with Missing Data in Palliative Care Trials: An Individual Participant-level Data Analysis of 10 Phase 3 Trials

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Background: Missing data can compromise the validity of trial findings, but we understand little about the factors associated with missing data and therefore how they can be reduced.

Aim: To assess the association of participant-, trial- and site-level factors with missing data in palliative care trials.

Methods:

Design: Individual participant-level data analysis of 10 phase 3 palliative care trials.

Data collection: Convenience sample which was not influenced by the extent of missing data.

Analysis: Multi-level cross-classified models were developed.

Results: Participants with a poorer performance status were more likely to have missing data for both the primary outcome and quality of life outcomes, at the primary follow-up point and end of follow-up. At the end of follow-up, more site randomisations and fewer site personnel were significantly associated with missing data.

Trial duration and the number of research personnel explained most of the variance at the trial and site-level respectively, except for the primary outcome where the amount of data requested was most important at the trial-level. Variance was more substantial at trial rather than site-level across models. Considerable variance remained unexplained for all models except the quality of life at the end of follow-up. Performance status was identified as a potential auxiliary variable for missing data imputation models.

Conclusion: This is the first study to establish that in palliative care trials conducted in high-income countries, participants with a poorer performance status are at higher risk of missing data and require additional support to provide complete data. Use of performance status in missing data imputation models could reduce bias and improve statistical power. Reducing trial variability should be prioritised, and further factors need to be identified and explored to explain the residual variance.

Abstract number: Q-06
Abstract type: Poster

Research Participation in Palliative Medicine - Benefits and Barriers for Patients and Families: Rapid Review and Thematic Synthesis

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Background: Research is essential for gathering the evidence needed to inform best practice and clinical decision making, for developing and testing new treatments and services in palliative and end of life care. The participation of patients, carers and family members is essential, however personal and ethical concerns are often cited as barriers to recruitment. There is some evidence highlighting perceived benefits of participation in research for this cohort.

Aim: To synthesise the evidence on patients', family members' and carers' experiences of participating in palliative and end of life care research and identify recommendations to enhance experience.

Design: A qualitative rapid review and thematic synthesis.

Data sources: MEDLINE, PsycINFO and PubMed were searched from 2010-2020. Studies reporting patients', family members' or carers' experiences of participating in palliative and end of life care research were included.

Results: 4 studies were included and 7 themes identified relating to the benefits of, and barriers to, participation in palliative and end of life care research. Both altruistic and personal benefits to participation were reported. Barriers (negative aspects) of participation included feeling overwhelmed, practical barriers, reminders of being a patient and unmet needs. The recommendations identified from this review, focus group and survey, include enhancing communication with participants and appreciating the researcher's role from the participant's perspective.
Conclusions: A number of benefits (positive aspects) surround participation in palliative and end of life care research. However, a number of barriers (negative aspects) can prevent or discourage participation. This review identified recommendations for research teams to enhance the experience, and the number of people who decide to participate in research in this field.
The review received no additional funding. LC, CH and BH's contribution was part of their roles at Marie Curie.

Abstract number: Q-07
Abstract type: Poster

Emotion Work and Emotion Management for Both Participants and Researchers in Interviews about Advanced Illness and End of Life Care

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Background: Undertaking research in sensitive topics can be emotionally challenging for both participants and researchers. The Thinking Ahead study explores how terminally ill patients from Black Asian and Minority Ethnic (BAME) backgrounds and their family care givers (FCGs) think ahead about deterioration and dying and whether and how they engage with healthcare professionals (HCPs) in end-of-life-care planning (EOLCP). This paper considers the experience and management of emotional labour of researchers and participant distress during data collection, acknowledging the importance of this neglected topic in research.
Aims: To explore the experience and management of emotion work for research participants and researchers in interviews about deterioration and dying among patients and their FCGs from BAME backgrounds.
Methods: Qualitative study including patient centred case studies and interviews with bereaved family caregivers. Reflective field notes were kept on the emotionality of interviews for researchers and participants and experiences discussed both as a formal debrief after each interview and within team meetings.
Results: 93 interviews in 18 case studies with patients, FCGs, and HCPs and 19 interviews with bereaved BAME FCGs were completed. Some participants described interviews as being emotionally burdensome causing anxiety whilst others reported these positive or even cathartic. Distress management of participants required careful consideration particularly when using interpreters. Researchers also found interviews to be emotionally challenging.
Conclusion: Undertaking research in end of life care can be challenging for participants and can have an emotional impact on the researchers. Such issues are an intrinsic part of the research process and should be discussed and reflected upon. A pyramid of support needs for participants was in place and preparatory and reflective resilience work, alongside regular support meetings for researchers was provided.

Abstract number: Q-09
Abstract type: Poster

Assessing the validity, reliability, acceptability and feasibility of the Integrated Palliative Care Outcome Scale (IPOS) in a South-East Asian Heart Failure setting: a mixed method study

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Background: The Integrated Palliative Care Outcome Scale (IPOS) is a survey developed in the United Kingdom (UK) for assessment of needs of patients with serious illnesses. IPOS can be self-reported or used by staff as a surrogate assessment. It is unclear if IPOS is culturally acceptable for use locally.
Aims: To describe the methodology involved in the assessment of the validity, reliability, acceptability and feasibility of IPOS use in the local heart failure (HF) care setting.
Methods: Using a prospective mixed methods design, we recruited English-speaking inpatients and outpatients who had a clinical diagnosis of HF and who were aged 21 years and above. All clinical staff involved in HF care were recruited.
For assessment of test-retest reliability/sensitivity to change, the patient and staff IPOS was administered at baseline and within 2 weeks after the first assessment. Pearson's correlation coefficient of the total IPOS score at baseline, with the total Minnesota Living with Heart Failure Questionnaire (MLHF) score and the total Edmonton Symptom Assessment System (ESAS) score was used to assess validity. We will also evaluate inter-rater reliability and internal consistency of IPOS. Semi-structured interviews with patients and staff on the acceptability of IPOS will be conducted.
Results: To date, we recruited 92 patients (mean age 56.6 years; 72% males, 54.3% Chinese) and 12 staff. Preliminary analysis showed a statistically significant strong correlation of IPOS with MLHF and ESAS (r= 0.89;0.86 respectively). Ten patients and 5 staff have been interviewed. Whilst participants felt IPOS was easy to understand, participants shared possible difficulties regarding implementation of IPOS into standard clinical care.
Conclusion: The mixed method design has allowed us to triangulate and collect data that is grounded in actual user experience, giving us a comprehensive picture of the real-world utility of IPOS. This has implications on future implementation plans.

Abstract number: Q-10
Abstract type: Poster

Informing Simulation-based Research Design: The Experiences of Bereaved Parents and Actors

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Background: Parents are being engaged in simulation development and educational initiatives in paediatric health care as realistic simulations are the most effective. There is increasing interest in the applicability of simulation as a research method. For studies involving simulated clinical encounters related to a child's end of life, involving bereaved parents in design is possible but not described. Bereaved parents are ethically and logistically the most accessible, but there are concerns about the safety of their involvement in such activities.
Aim: To explore the experiences of bereaved parents and actors when informing simulation-based research design.
Methods: This qualitative study adopts an interpretivist research paradigm. Following a group meeting to design and develop characters to be used in a simulation, five bereaved parents and two actors participated in individual semi-structured telephone interviews, which were audio recorded. Data from the transcripts underwent inductive content analysis.

Results: Four experiences were explored: (1) the recruitment approach of parents, (2) the facilitation and format of the group meeting, (3) the motivation and impact of participation on the parents, and (4) the motivation and impact of participation on the actors. While the meeting was emotionally challenging for bereaved parents, they were motivated and committed to its success. Parents also identified a therapeutic benefit in sharing their stories. For actors, this exposure to reality, re-confirmed the importance of their work, provided 'gold' for their roles, and elicited emotion that challenged their self-protective mechanisms.

Conclusions: The involvement of bereaved parents in simulation design is safe and beneficial, for both parents and the actors involved in the simulation. Ongoing involvement of bereaved parents may lead to higher-quality simulated experiences, which hopefully will enhance care provided at a child's end of life.

Abstract number: Q-11
Abstract type: Poster

Outcomes and Measures of Delirium Interventional Studies in Palliative Care to Inform a Core Outcome Set: A Systematic Review

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Background: Trials of interventions for delirium in various patient populations report disparate outcomes and measures but little is known about those used in palliative care trials. A core outcome set promotes consistency of outcome selection and measurement.

Aim: To inform core outcome set development by examining outcomes, their definitions, measures and time-points in published palliative care studies of delirium prevention or treatment delirium interventions.

Methods:

Design: Prospectively registered systematic review adhering to Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Data sources: We searched six electronic databases (1980-November 2020) for original studies, three for relevant reviews, and the International Clinical Trials Registry Platform for unpublished studies and ongoing trials. We included randomised, quasi-randomised, and non-randomised intervention studies of pharmacological and non-pharmacological delirium prevention and/or treatment interventions.

Results: From 13/3244 studies (2863 adult participants), we identified nine delirium-specific and 13 non-delirium specific and outcome domains within eight Core Outcome Measures in Effectiveness Trials (COMET) taxonomy categories. There were multiple and varied outcomes and time points in each domain. The commonest delirium specific outcome was delirium severity (n=7), commonly using the Memorial Delirium Assessment Scale (6/8 studies, 75%). Four studies reported delirium incidence. Non-delirium outcomes included mortality, agitation, adverse events, other symptoms, and quality of life.

Conclusion: The review identified few delirium interventions with heterogeneity in outcomes, their definition and measurement, highlighting the need for a uniform approach. Findings will inform the next stage to develop consensus for a core outcome set to inform delirium interventional palliative care research.

Abstract number: Q-12
Abstract type: Poster

Using EQ-5D-5L in palliative care – how feasible is longitudinal measurement in a community dwelling cohort of patients with advanced colorectal cancer approaching death?

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Background: EQ-5D-5L is a generic preference-based measure of health-related quality of life (QoL), often used to calculate quality-adjusted life years for application in cost-effectiveness analyses. Understanding how EQ-5D-5L changes over time and towards death in people living with advanced cancer is important for measuring the effectiveness of palliative care interventions.

Objective: To describe how close-to-death self-reported EQ-5D-5L data can be collected from community dwelling adults living with advanced colorectal cancer, and how EQ-5D-5L changes over time and in proximity to death.

Method: EQ-5D-5L was collected as part of a prospective cohort study (the Palliative Care Early and Systematic [PaCES] Project). Participants were recruited from medical oncology out-patient clinics and completed the EQ-5D-5L online, by phone, or by mail, per preference (monthly in year 1, every 3 months thereafter). Enrollment and data collection occurred from Jan 2018-Dec 2020 or until death.

Results: Of 131 participants, death occurred in 102 (78%). The median number of surveys collected per decedent was 7 (IQR 4-10), with a median of 244 days on study (10-396), and a median duration from last survey response to death of 41 days (IQR 26-74).

At enrollment, decedents' median EQ-5D-5L index value (where 1.0=full health) was 0.85 (IQR 0.77-0.91) and self-rated health on a vertical visual analogue scale (VAS; 0=worst, 100=best) was 75 (IQR 60-85). Decedents last reported EQ-5D-5L index value was median 0.77 (IQR 0.59-0.86) and VAS 50 (35-70), indicating significant change from enrollment for both these QoL measures ($p_{\text{Mann-Whitney U}} < 0.001$).

Conclusion: It is feasible to collect self-reported EQ-5D-5L data longitudinally and up to two months prior to death for community-dwelling advanced cancer patients. EQ-5D-5L may allow description of QoL changes prior to death and in relation to palliative care interventions.

Abstract number: Q-13
Abstract type: Poster

Methodological Aspects of Economic Evaluations Conducted in the Palliative and End-of-Life-care Settings: A Systematic Review

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Aim of the work: This study is part of iLIVE, a EU funded research that aims, amongst other, to identify and summarize relevant information on the methodological aspects for conducting economic evaluations in the palliative or end-of-life care settings. This information is of high relevance as the generation of valid and useful evidence and decision base for service development requires that research methods applied in the palliative care or end-of-life care fields consider the specific conditions of these settings in their methodology. However, common research guidance is lacking, especially regarding the methods applied in economic evaluations.

Design, methods: A systematic review has been conducted following the methodology described in a published research protocol. Pre-designed forms have been used for data extraction, followed by narrative synthesis and critical appraisal.

Results: Our search strategy yield 5030 references, of these 121 references were included after abstract and title and full-text screening. We identified information on methodological challenges, potential solutions and recommendations for conducting economic evaluations in the palliative and end-of-life care settings, with regards to research and trials in general (8%), the target population (4%), the study perspective (8%), the setting and location (6%), measuring outcomes (including adaptions of QALYs, capabilities, alternative self-reported outcome measures) (32%), valuation (13%), assessing costs (e.g. inventory of costing frameworks) (23%) and other factors (5%).

Conclusion: The findings of this systematic review should help to clarify current methodological questions, prioritize future methodological research studies and standardize the methodology and execution of future economic evaluations, which should increase their comparability and overall transparency.

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Abstract number: Q-14
Abstract type: Poster

Causal Analyses of Palliative Care Using Observational Data: A Review of Current Literature and Consideration of Future Opportunities

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Background: Palliative and end-of-life care studies rely heavily on routinely collected data but observational studies face a high risk of bias. Causal analyses with observational data are increasingly popular in social sciences. We are unaware of any prior review examining the use of causal inference methods with observational data in palliative care.

Aims: We aim to identify, organize and report the evidence on causal inference with observational data in palliative populations and consider how these methods might be applied more widely to bridge established evidence gaps.

Methods: A systematic literature search was conducted on seven databases: EMBASE, Medline, Cochrane Library online database, CINAHL, EconLit, Web of Science, and SCOPUS. Grey literature search was executed on NBER, SSRN and Arxiv. Eligible interventions were programs or services for palliative care. Eligible outcomes were costs, health care use and quality-of-life outcomes. Eligible study designs were those that controlled for unobserved confounding, generating a causal treatment effect estimate using observational data. Quality assessment based on STROBE and data extraction based on Cochrane data extraction form.

Results: The database search returned 684 results and the grey literature search identified no additional studies. After excluding duplicates, we screened 311 unique titles/abstracts and 27 full texts. The full-text review identified eligible 14 papers: eight used difference-in-differences methods, four used interrupted time series analysis, and two used instrumental variables. There was a wide variation in the quality of included papers. Studies reported a general pattern of improved outcomes associated with palliative care.

Conclusion / Discussion: Causal analyses with observational data are an underused tool in palliative and end-of-life care. Expanding the use of these methods alongside primary research studies is critical to addressing evidence gaps.

Abstract number: Q-15
Abstract type: Poster

Translation and Cross-cultural Adaptation of Integrated Palliative Care Outcome Scale (IPOS) in Hindi

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Introduction: Over the last three decades,various models of exemplary palliative care delivery have been implemented in India,however indigenous evidence of the complex interventions is missing.The patients' symptoms need impeccable assessment as per the WHO definition of Palliative care,for this valid instruments are needed.Thus, IPOS translation and validation was undertaken to make it conceptually equivalent and psychometrically valid for Hindi speaking people.

Methods: The study adopted five phase standardized methodology for translation and validation of IPOS in Hindi.1)Equivalence setting was achieved through a three steps process including literature review, cognitive testing with purposive sample of 11 palliative care professionals and two FGDs with patients.2)Forward translation in Hindi was completed with three independent translators.3)Blind backward translation was produced with another three independent translators.4) Back translated version was mapped by the expert panel of the original POS team.5)Qualitative pretesting and de-briefing was conducted with Hindi speaking patients through in-depth interviews.All interviews and FGDs were audio-recorded, transcribed and analyzed using content analysis approach.

Results: Phrases namely depression,anxious, overwhelmingly,practical problems were difficult and response categories namely occasional and sometimes were overlapping in Indian setting.Nausea, poor appetite, drowsiness and depression were difficult to translate in Hindi.Cognitive de-briefing suggested that all the items,instruction and response categories were simple to understand.

Conclusion: The Hindi IPOS has face and content validity for research and clinical practice.The Hindi IPOS has implications beyond Indian palliative care settings. Millions of Hindi speaking population can now respond to IPOS for recognizing their palliative care needs in their mother tongue without translators.Psychometric testing of Hindi IPOS is underway for future progress.

Abstract number: Q-16
Abstract type: Poster

Exploring Conditions that Render Patients too Unwell to Participate: Challenges from the RAMBO Study

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Inoperable malignant bowel obstruction (IMBO) is a distressing, under researched condition affecting those with advanced cancer. Symptoms include nausea, vomiting, distension, colic, pain and constipation, which have a profound effect on quality of life. There are limited data regarding the challenges of recruiting patients with IMBO in qualitative research.

To determine the reasons why patients with IMBO did not take part in the Research Assessment of Malignant Bowel Obstruction Study (RAMBO).

Recruitment logs of patients with IMBO screened to take part in semi-structured interviews, were split into those not approached and those approached, but unable/unwilling to participate. Information collected included gender and reason for not participating/not approached.

So far, 7/27 eligible patients have been interviewed; 20 patients (15 women, 5 men) did not take part. Reasons for not being approached (N=18) included: physical (too unwell n=9); psychological/emotional (distress, shock n=3); inability to consent (n=2); care/management (surgical review, complex management n=3); deceased - sudden decline (n=1). Two participants were approached; both were interested to take part, however one suddenly declined and the other felt their experience too traumatic to discuss.

This study highlights consistent challenges of ensuring patients with serious complications of cancer are heard in research. Even those with capacity to consent are deemed too unwell to approach/participate due to their physical or psychological condition and risk of sudden decline. While overzealous clinicians' gatekeeping has been noted in palliative research, the issues presented fit with the challenging nature of identifying an appropriate clinical window during which patients might participate. To include such patients in qualitative research, teams must be agile, responding promptly for data collection, and able to adapt interview strategies.

Abstract number: Q-17
Abstract type: Poster

Using Focus Groups Methodology for Sensitive Topics in End of Life Research - The Conversation Continued

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Objectives: To present an exploration of the experiences of using focus group methodology to discuss end of life family conversations in families of African and Caribbean heritage; And to explore the change of dynamics of these focus group discussions when COVID 19 required a change from in person discussion to synchronous online discussions.

Background: Individual interviews are widely used in qualitative research when exploring sensitive topics such as discussions with people who are dying or around the dying of others. Previous studies have explored many issues that arise in carrying out palliative care research. They have focused on ethical appropriateness, benefits and burdens and consent. When exploring the use of focus group methodology in sensitive research, issues such as confidentiality, anonymity, power imbalances between participants and risk of harm have been concerns. With the rise of participatory forms of research entering the palliative care arena, interest has grown and confidence has been built in utilising group discussions to generate a greater flow of ideas.

Method: Process and outcome analysis of five focus groups of people from African and Caribbean heritage discussing end of life family conversations. Two focus groups were undertaken in person and three were conducted online.

Results: The process analysis revealed a dynamic of power rebalancing. The groups had more participants than facilitators and the impact of this was noticeable, particularly in the group of older people where participants supported each other to focus on themes that were significant to them. The presence of two group facilitators, a common feature of focus groups provided insightful opportunities for reflexivity. Moving from in person groups to online groups altered the ratio of comments between facilitators and individual participants than between participants. Outcome analysis revealed that fewer themes were generated in the online groups.

Abstract number: Q-18
Abstract type: Poster

Engaging the Public in Talking about Death and Dying: Methodological Learning

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Background: We have little knowledge about public opinion on death and dying in the UK. Previous studies have focused on specific groups e.g. older people or those with life limiting conditions. This paper presents deliberative discussion groups as a novel methodology for investigating the topic which proved adaptable to online data collection following Covid-19 restrictions.

Aim: To engage the UK public in discussion about death and dying.

Method: Deliberative discussion groups of different topics over four sessions with a range of members of the public. Participants were provided with information resources prior to each meeting as a spur to thought and differing perspectives. Five individual interviews were also undertaken with participants who were unable to attend groups. A thematic approach to analysis was used.

Results: Seven discussion groups and five individual interviews involving 41 participants (men n=9/women n=32, age range 30-81yrs).

Discussion: We identified three key areas of methodological learning:

1) Recruitment to online groups allowed wider geographical reach and opened contact with sections of the population that would not otherwise have been available e.g. those usually at work. However, the constraints of Covid-19 reduced our ability to recruit by making direct contact with some groups, such as ethnic minorities and younger age groups.
2) Deliberative discussions were an effective way to build rapport among participants and encourage detailed consideration of key topics. Feedback from participants was overwhelmingly positive.
3) Moving to online data collection proved to be feasible, with scheduling made easier, more convenient and cost effective. There were some technical issues, but participants generally considered it to be a convenient way to participate. The online format worked best with smaller groups and shorter sessions, and also without presentation of interactive resources during the discussion.

Abstract number: Q-19
Abstract type: Poster

Preliminary Results from the Compassionate Leadership Scale in Palliative Care Professionals

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Background: Leadership styles are essential in the field of Health. Those centered on relationships stand out over those that focused on tasks. In this sense, compassion is key to strengthen employees relations one to another in meaningful ways. Specifically in healthcare, compassion has proved to hastening the post-trauma healing process. In this context, compassionate leadership play an important role.

Aims: To study the characteristics of an adaptation of the Compassionate Leadership Scale (CLS) in palliative care professionals.

Methods:

Design: The research has a panel design, in which palliative care professionals participate during years 2020-2022. Data collected in the first wave are used.

Data collection: 296 professionals participated. An adaptation of the CLS, which measures attending, understanding, empathizing, and helping, was used.

Analysis: Statistical analyses will include descriptive information, reliability estimates and inferential analyses.

Results: Levels of CLS were adequate, with higher levels in attending. Reliability estimates were good, with alphas over .70.

No differences in compassionate leadership were found between physicians and nurses.

Positive relations between both compassion for others and self-compassion and compassionate leadership were found, with compassion for others having the higher predictive power.

Compassionate leadership was also related to better professional quality of life, with higher levels of compassion satisfaction and lower levels of burnout being related with higher levels in compassionate leadership.

Conclusion: This adaptation of CLS can be used to detect compassionate leaders in healthcare. Leaders could be modelling compassionate behaviors, and their acts of compassion can have a powerful impact on the work culture.

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Abstract number: Q-21
Abstract type: Poster

Study of the Phenomenon of Gatekeeping in French Palliative Care Physicians

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Background: Including patients in studies on palliative care is one of the main difficulties encountered, even though patients seem to be in favour of taking part in them. However, a phenomenon has been described in English-speaking countries: "gatekeeping", " When healthcare professionals or other involved parties prevent eligible patients from entering a trial as a research subject". This phenomenon is responsible for up to 25% of causes of a patient not having access to a study. To study this phenomenon in France, we focused on the representations of the investigating palliative care physicians, concerning the participation of patients in clinical trials.

Methods: An ethnographic qualitative pilot study using semi-structured interviews was conducted, with the aim of questioning French palliative care physicians who had taken part in research. A thematic analysis was carried out by a multidisciplinary team (comprising a methodologist, a sociologist and a physician). The study had been approved by an ethics committee.

Results: 7 interviews of physicians (average 51min) with a variety of profiles were analysed. The representations held by the physicians concerning the participation of patients seem to be ambivalent, linked to the very perception they have of research in palliative care. Thus, the gatekeeping appears necessary but also presents the image of a lack of scientific rigour based on the physician's subjective vision. The reasons for gatekeeping vary, but they seem to reflect their personal/professional experience and value conflicts. The main avenue for curbing this phenomenon lies in training physicians and research teams. That also leads to a greater involvement of the actors of research in writing protocol methodology.

Conclusion: This pilot study underlines the existence of a value conflict between palliative care and research. This conflict is more or less significant with regard to the individual's professional socialisation.

Abstract number: Q-22
Abstract type: Poster

Conducting Focus Groups Online due to the Pandemic – Trick or Treat?

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Aim: Due to the COVID-19 pandemic, we had to conduct focus groups online instead of face-to-face. Data on online focus groups (OFG) are scarce. We aim to describe our experiences and participant feedback of OFG.

Methods: 4 topic guide-led OFG with nurses and physicians via video-calls (*zoom*). Total time planned for each focus group, including a short introduction, was 2 hours. Number of participants ranged from 4-9. 2 researchers facilitated the OFG with one focusing on technical support, if required. After discussion about our research topic (sedation in specialist palliative care), we asked for participant feedback.

Results: OFG require thorough preparation, especially regarding the choice of the videocall-platform and the method of recording. We had to balance issues of accessibility from hospital networks, usability and data protection. OFG were easier to schedule as travelling was unnecessary – a feature appreciated by participants.

Participant briefing was crucial – both from participant and researcher perspective. We offered a test call to minimize technical problems and agreed upon a 'videocall etiquette' to enable a "natural" discussion and a comfortable atmosphere - which had positive effects on the discussion. Participants noted that they did not feel hindered in expressing their views by the online format and appreciated the professional exchange during the pandemic.

Facilitating the discussion proved challenging, since giving non-verbal clues or subtly 'activating' participants was hardly possible via videocall. Therefore, we chose a more direct approach in moderating, often addressing individual participants by name.

Conclusion: In our experience, OFG can be a useful tool for collecting data. Sound preparation taking OFGs' features into account is paramount in order to establish a comfortable and productive videocall atmosphere.

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Abstract number: Q-23
Abstract type: Poster

Validity and Reliability of the English and Translated Chinese Versions of the Integrated Palliative Care Outcome Scale (IPOS) in Singapore

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Background: Measurement of patient-centred outcomes enables clinicians to focus on patient and family priorities.

Aims: This study aimed to evaluate the validity and reliability of the English and translated Chinese IPOS among advanced cancer patients in Singapore.

Methods: IPOS was forward and backward translated from English into Chinese. Structural validity was assessed by confirmatory factor analysis;

known-group validity by comparing inpatients and community patients; construct validity by correlating IPOS with Edmonton Symptom Assessment System-revised (ESAS-r) and Functional Assessment of Cancer Therapy–General (FACT-G); internal consistency by Cronbach's alpha; inter-rater reliability between patient and staff responses; test-retest reliability of patient responses between two timepoints.

Results: 111 English-responding and 109 Chinese-responding patients participated. The three-factor structure (Physical Symptoms, Emotional Symptoms and Communication and Practical Issues) was confirmed with Comparative Fit Index and Tucker-Lewis-Index >0.9 and Root Mean Square Error of Approximation <0.08. Inpatients scored higher than outpatients as hypothesised. Construct validity (Pearson's correlation coefficient, $r\geqslant|0.608|$) was shown between the related subscales of IPOS and FACT-G and ESAS-r. Internal consistency was confirmed for total and subscale scores (Cronbach's alpha$\geqslant$0.84), except for the Communication and Practical Issues subscale (Cronbach's alpha=0.29-0.65). Inter-rater reliability (Intra-class correlation coefficient [ICC]$\leqslant$0.43) between patient and staff responses was insufficient. Test-retest reliability was confirmed with Intra-class correlation coefficient ICC=0.80 (English) and 0.88 (Chinese) for IPOS Total.

Conclusion: IPOS in English and Chinese showed good validity, good internal consistency, and good test-retest reliability, except for the Communication and Practical Issues subscale. There was poor inter-rater reliability between patients and staff.

Abstract number: Q-24
Abstract type: Poster

How to Measure the Impact of Complementary Therapies in Palliative Care: A Systematic Review to Identify and Evaluate the Appropriateness and Validity of Multi-domain Tools

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Background: Massage, reflexology and aromatherapy are complementary therapies (CT) commonly provided in palliative care. People at a palliative stage report positive benefits of CT in qualitative research, however trial evidence on effectiveness is inconclusive. This may, in part, be due to the use of inappropriate measurement tools.

Aims:

1) Identify multi-domain tools (which go beyond physical symptoms) used to evaluate massage, reflexology and aromatherapy in randomised control trials, and
2) Evaluate psychometric properties of tools identified which were developed or validated in palliative populations.

Methods: A two-stage systematic review:

(1) identify tools used in trials of massage, reflexology and aromatherapy;
(2) evaluate the methodological quality of studies and psychometric properties of tools.

Six databases were searched from inception to December 2019 (stage 1) and July 2020 (stage 2). Methodological quality and psychometric properties were assessed using COnsensus-based Standards for selection of health Measurement Instruments (COSMIN) checklist. Evidence quality was evaluated using Grading of Recommendations Assessment, Development and Evaluation (GRADE). A scoring system (-4 to +4) was applied to compare tools.

Results:
Stage 1: 55 trials were identified using 34 different multi-domain tools.
Stage 2: 13 papers identified in which 6 of the identified tools were developed or validated in palliative populations.
The evidence was mostly of low quality. Use of modified tools made assessment difficult. Where synthesis occurred, the majority of psychometric data were inconsistent or inconclusive. The Functional Assessment of Cancer Therapy – General (FACT-G) was the highest scoring tool (+2).

Conclusion: Of the available tools, we recommend FACT-G for future trials of CT in palliative care, but further research is needed to develop and validate tools in palliative populations.

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Abstract number: Q-25
Abstract type: Poster

Investigation of Care Models in Cancer Patients Receiving Palyative Care: A Systematic Review

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Background: Care models increase the health levels and quality of life of patients and their relatives clinically together with scientific information support and nursing practices.

Aims: This systematic review aims to investigate and systematically appraise care models used in cancer patients receiving palliative care.

Methods: The Pubmed, Scopus, WOS, ScienceDirect, and Medline databases were searched for the keywords of model, nursing, cancer, and palliative care, and the studies published between January 2013 and 2020 were appraised. Reviews, letters, book chapters, congress reports, or case reports were not included in the study. The PRISMA 2015 checklist and Cochrane methodology were used to meet the systematic review criteria.

Results: 10 of 782 studies were examined in the study. One of the studies was a randomized controlled experimental study and 5 of them were qualitative studies. The models used in the study were Integrated Model (2), Kerala Model, Nursing Based Counseling Model, Palliative Rehabilitation Model, COMFORT Model, SAGE & THYME Communication Model, Compassion in Care Model, SPARK Model, and Early Palliative Care Model. Studies were mostly of high quality. The use of models increased the quality of patient care and satisfaction, and nurses help in providing self-confident and conscious care.

Conclusion: Using models and conducting randomized controlled studies with higher levels of evidence for the quality of care models are recommended.

Keywords: model; nursing model; nursing; cancer; palliative care; systematic review

R Posters COVID 19

Abstract number: R-04
Abstract type: Poster

Factors Associated with Busyness among Hospice and Palliative Care Services during the COVID-19 Pandemic: An International Survey (CovPall)

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Background: Palliative care and hospice services responded to the Covid-19 pandemic, but it is not clear how their workload has been affected.
Aim: To identify factors associated with busyness in UK palliative care services during the Covid-19 pandemic.
Methods: Online survey of clinical leads of palliative care services to understand the palliative care response to COVID-19 (CovPall). Study population characteristics were described. Unadjusted and multivariable ordinal logistic regression investigated factors (type of service, management type, number of confirmed (by test) Covid-19 cases, region, staff shortages) associated with busyness. Busyness was measured using a five-point scale (a lot less busy, slightly less busy, about the same, slightly more busy, a lot more busy).
Results: 277 UK respondents: 33 Scotland, 4 Northern Ireland, 15 Wales, 225 in nine regions of England. Services reported being a lot more busy (71, 26%), slightly more busy (62, 22%), about the same (53, 19%), slightly less busy (50, 18%), much less busy (28, 10%). Multivariable analysis showed the following factors were associated with increased busyness: being a specialist palliative home care service (OR 1.93, 95% CI 1.15-3.25), providing hands on nursing care at home or in the community (OR 3.24, 95% CI 1.70-6.19), confirmed number (by test) Covid-19 cases (OR 1.01, 95% CI 1.00-1.01), being a publicly managed (NHS) service (OR 2.20, 95% CI 1.11-4.34), and experiencing staff shortages (OR 2.71, 95% CI 1.64-4.48).
Conclusion: Community services and those publicly managed (NHS services) experienced increased busyness during Covid-19 pandemic. This suggests these services may have been more able to shift resources to respond to increased needs and changing patient priorities during the pandemic. This has implications for future funding models for palliative care.

Abstract number: R-05
Abstract type: Poster

Lessons Learned by the Dutch Palliative Care Expert Group from the First COVID-19 Wave

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Aim: To quickly develop practical guidelines based on clinical urgencies for palliative care patients during Covid-19.
Approach: To unlock knowledge and to tackle emerging problems in palliative care caused by Covid-19, the Dutch cooperation of palliative care launched an expert group, consisting of palliative care practitioners and researchers in all settings around the country. During the first wave the experts gathered twice-weekly in online meetings.
Results: The expert group produced guidelines about Covid-19 symptom management; oxygen use at home; advance care planning including a format to share outcomes; supportive care for loved ones; handling possible shortages in (sedative) medication. All were authorized by national professional organizations. Besides these tangible results, conversations provided valuable insights about the impact of Covid-19 on palliative care and the contribution that palliative care professionals can make:

- Covid-19 showed that each person, especially aged or fragile, can get life-threatening sick quickly. ACP should be promoted actively among all fragile: ACP must be as planned as a population screening.
- To meet patient wishes and to relieve IC's, palliative care at home should be strengthened, provision of expert advice and appropriate resources are needed.
- Being familiar with death and dying, rituals, anticipatory and disturbed grief, palliative care professionals must support colleagues in caring for dying patients.
- Sharing experiences and emotions need a structural place during hectic times.
- A lack of knowledge about a disease, its trajectory and patients' needs is disabling. Research and palliative care must always go hand in hand.

Conclusion: Corona showed that problem oriented innovative collaboration can unleash an enormous vigor to get work done. By sharing expert insights with professionals, volunteers, policy makers and public administration (future) Covid-19 care can be improved.

Abstract number: R-07
Abstract type: Poster

Pharmacological Strategies Used to Manage Symptoms of Patients Dying of COVID-19: A Rapid Systematic Review

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Background: COVID-19 has tragically resulted in over 2 million deaths globally. Despite this, there is a lack of research on how to care for patients dying of COVID-19, specifically pharmacological management of symptoms.
Aims: The aim was to determine the dose ranges of pharmacological interventions commonly used to manage symptoms in patients dying of COVID-19, establish how effectiveness of these interventions was measured, and whether the pharmacological interventions were effective.
Methods: This was a rapid systematic review with narrative synthesis of evidence, prospectively registered on PROSPERO (ID: CRD42020210892). We searched MEDLINE, EMBASE, CINAHL via the NICE Evidence Health Databases Advanced Search interface; medRxiv; the Cochrane COVID-19 Study Register; and Google Scholar with no date limits. We included primary studies which documented care of patients dying of COVID-19 under the care of a specialist palliative care team.
Results: Seven studies, documenting the care of 493 patients met the inclusion criteria. Approximately two thirds of patients required a continuous subcutaneous infusion with median doses of 15mg morphine and 10mg midazolam in the last 24 hours of life. Four studies described effectiveness by retrospective review of documentation. One study detailed the effectiveness of individual medications.
Conclusions: A higher proportion of patients required continuous subcutaneous infusion than is typically encountered in palliative care. Doses of medications required to manage symptoms were generally modest. There was no evidence of a standardised yet holistic approach to measure effectiveness of these medications and this needs to be urgently addressed.

Abstract number: R-11
Abstract type: Poster

Vulnerability and Resilience: An Ethnographic Study among Incurable Cancer Patients during COVID-19 in the Netherlands

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Background: Little is known about the impact of the COVID-19 crisis on patients living longer with incurable cancer. Since patients did not reach the end-of-life phase yet, new challenges to guarantee appropriate care arise.

Aims: To explore the experiences of patients with protracted incurable cancer during the COVID-19 crisis, focusing on daily concerns and changes in care.

Methods: Qualitative study based on 11 semi-structured in-depth Zoom interviews and 6 follow-up interviews (focus on incurable patients), with (online) observations of group talks at 3 cancer Walk-in houses (curable and incurable patients). Analysis was informed by grounded theory, using thematic analysis.

Results: For most respondents, cancer remained their prime health concern, although COVID-19 added insecurity to their already limited prognosis and hampered meaningful activities and social contacts. COVID-19 created an unwanted confrontation with respondents' vulnerability. Nevertheless, they found strength in rejecting the notion that this vulnerability stretched beyond their physical state. Moreover, respondents reported feeling better equipped to deal with the situation because of their disease, as a loss of control, freedom, possibilities, and risk of death were already familiar. Respondents focused on practicing acceptance and gratitude, finding a sense of rest due to limited commitments. Restrictions could, however, impact respondents' ability to 'make memories' in the limited time they had left, creating a sense of 'Lost Time'. They tried not to linger on such thoughts, focusing on hope and their belief of time left after this COVID-19 period.

Conclusion: Patients living longer with incurable cancer, now spend their limited time with extensive restrictions. However, respondents managed incurable cancer, finding resilience despite, as well as because of their disease. More research is needed to further capture this interplay between vulnerability and resilience.

Abstract number: R-13
Abstract type: Poster

An Online Survey among Health Care Professionals about End-of-Life Care for Patients Dying during the First and the Second Wave of the Pandemic of COVID-19: The CO-LIVE Study - Czech National Data

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Background: COVID-19 has caused an ongoing pandemic crisis and it has a great impact on health care worldwide. The situation in the Czech Republic was well controlled at the first wave of COVID-19 because of strict restrictions but it got worse during the second wave.

Aim: The goal of this study was to compare the impact of the pandemic of COVID-19 on end-of-life care during the first and the second wave.

Methods: This study was an online questionnaire survey to assess experiences of end-of-life care during the pandemic among health care professionals providing care for dying patients either during the first wave (March 2020 - May 2020) and the second wave (October 2020 - February 2021). Data were collected online using snowball and convenience sampling using dissemination through relevant professional organisations and personal contact. The questionnaire was an abbreviated version of the international Care Of the Dying Evaluation (iCODE) questionnaire with additional questions about the impact of COVID-19. The differences in 2 waves were compared using Cramer's V.

Results: 136 health care professionals completed the survey at the first wave and 116 at the second wave, most of them were nurses (58 % and 84 %). Experience from both surveys did not differ regarding nursing care which was considered sufficient (88 % vs 89 %). In both samples, only 10 % of professionals thought that end-of-life care had to be limited because of the pandemic. In the second wave, there was a significant decrease in the reported level of comfort provided for patients (p= 0.01), in the level of emotional support for family carers (p= 0.005) and significantly fewer professionals thought that their patients died at the right place (64 % vs 47 %).

Conclusion: This study shows that although the medical aspect of end-of-life care might have not been affected during the pandemic, psycho-social care has been affected and it might have a long-lasting impact on relatives, as well as on professionals.

Abstract number: R-16
Abstract type: Poster

Advance Care Planning during the Covid-19 Pandemic: A Content Analysis of Newspaper Coverage

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Background: The Covid-19 pandemic made abundantly clear that we all may suddenly fall severely ill and may find ourselves in need of a care plan. Advance care planning (ACP) may provide support to patients in these circumstances. It is unknown if and how the relatively new concept of ACP is portrayed and presented to the general public in newspapers during the pandemic.

Aims: To investigate newspaper coverage of ACP during the Covid-19 pandemic.

Methods (design, data collection, analysis): From LexisNexis Uni, an international electronical archive of newspapers, we included articles about ACP and Covid-19, in English or Dutch, published in 2020. We conducted a descriptive content analysis. Using a standardized form, we extracted data about the articles (date of publication, country), their conceptualization of ACP and how ACP was portrayed.

Results: We found 134 eligible articles. Articles were mainly published in April 2020 (73 articles; 54%) and in newspapers published in the United Kingdom (n=59), Canada (n=32) or the United States (n=15). Sixty-three percent of the articles explained what ACP is, the others mentioned ACP without explanation. In 81% of the articles, possible treatment and care options for Covid-19 were discussed, mostly cardiopulmonary resuscitation (38%), artificial ventilation (31%), admission to the hospital (34%) or admission to the intensive care unit (16%). In sixty-six percent of the articles readers were encouraged to engage in ACP, for instance to discuss care preferences (70 articles; 52%) or to make a living will (53 articles; 40%).

Conclusion / Discussion: This study shows that ACP was part of the public discourse during the Covid-19 pandemic in many countries. Most articles were published at the start of the pandemic and focused on treatment decisions, such as DNR orders. The majority of the articles encouraged the public to engage in ACP, especially to discuss care preferences and make a living will.

Abstract number: R-17
Abstract type: Poster

Dying in the Midst of a Pandemic: A Qualitative Study of Bereaved Relatives' Experiences about their Family Members Deaths

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Background: The global COVID-19 pandemic is having a major impact on experiences of dying and death. Family members perceptions about the quality of care for dying individuals and their preparedness for death may influence their psychological adjustment in grief.

Aim: To explore relatives' experiences and needs when their family member was dying during the COVID-19 pandemic to help inform current/future clinical practice and policy.

Design: Participants, who had responded to a national on-line COVID-19 survey, were invited to participate. Semi-structured interviews were conducted (via telephone or video-call) with relatives whose family member died during the pandemic. Data were analysed thematically.

Results: 19 participants (12 female, 7 male) reflected experiences of deaths within hospital and care home settings, with and without COVID-related illness. Three themes were identified: (1) entering the final weeks and days of life during a pandemic, (2) navigating the final weeks of life during a pandemic, and (3) the importance of 'saying goodbye' in a pandemic. In the absence of direct physical contact, it was important for families to have a clear understanding of their family member's condition, declining health and detailed, holistic information about their wellbeing. Staying virtually connected with them in the final weeks/days of life and having the opportunity for a final contact before death were fundamentally important. Health and social care professionals were instrumental to providing these aspects of care but faced practical challenges in achieving these.

Conclusions: Health and social care professionals have an important role in mitigating the absence of relatives' visits at end of life during a pandemic. Strategies include prioritising virtual connectedness, ensuring holistic, individualised care updates and creating alternative opportunities for relatives to 'say goodbye'.

Abstract number: R-18
Abstract type: Poster

Was End-of-Life Care Limited during the First And Second Wave of the COVID-19 Pandemic? An Online Survey among Healthcare Professionals Working in Different Settings. (Co-Live)

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Background: How COVID-19 has impacted end-of-life care in the Netherlands may differ between the first and second wave, as for instance in the second wave visiting restrictions were less strict. We can learn from data of the two waves of this pandemic and the impact on end-of-life care for future waves or other pandemics.

Aim: To describe to what extent end-of-life care was limited due to the COVID-19 pandemic according to healthcare professionals in different settings during the first and second wave of the pandemic in the Netherlands.

Methods: An open online survey between November 2020 and February 2021 among health care professionals who provided end-of-life care during the first and second wave of the COVID-19 pandemic in the Netherlands (between March 2020 and February 2021). We tested differences between healthcare settings and waves using confidence intervals.

Results: 255 healthcare professionals (42 physicians, 199 nurses, 66 other healthcare workers) from different settings. In all settings, psychosocial care and spiritual care were more often limited compared to nursing care and medical care in both waves. For all aspects, except medical care, care was most often limited in nursing homes and hospitals, in both waves. Overall, more than half of the healthcare workers said that psychosocial care (57%), spiritual care (55%) and preparing patients and relatives for death (53%) were limited during the first wave. With resp. 31%, 30% and 22% these percentages were lower in the second wave.

Discussion: Especially psychosocial and spiritual care were limited, possibly due to a focus on preventing infections with measures such as physical distance and visiting restrictions. Since psychosocial and spiritual aspects are essential for good end-of-life care, it is important to weigh pros and cons of preventing infections and limiting psychosocial and spiritual care. This seems to have been done better in the second wave.

Funding: ZonMw

Abstract number: R-19
Abstract type: Poster

Are Public Health Measures and Individualised Care Compatible in the Face of a Pandemic? Bereaved Relatives' Experiences of End-of-Life Care during a Pandemic

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Background: Measures put in place to modify the COVID-19 infection rate, may have jeopardised typical end-of-life care values, focused on individual needs and preferences, such as the wish not to die alone.

Aim: To understand bereaved relatives' perceptions about the dying experience during the pandemic.

Methods: A national online survey, informed by patient and public involvement, was developed and disseminated via social media, public and professional networks (June - September 2020). Validated instruments and purposively designed questions were used to assess experiences. Analysis used descriptive statistics, logistic regression and thematic analysis of free-text responses.

Results: Respondents (n=278) had a mean age of 53.4 years; 216 (78.0%) were female and 174 (62.6%) were the 'child' to the deceased. Almost 70% of the deceased (mean age 80.5 years; 160 (57.6%) female) died in their 'usual place of care' (home n=30 (10.8%); nursing home n=162 (58.3%)).

Quantitative survey data and qualitative free-text responses indicated: public health restrictions compounded the distress of 'not knowing' (156, 56.5% were unable to visit during the dying phase of illness); greater confidence and trust in nursing staff compared with medical staff (81.6% vs 57.4%); lack of preparedness (19.9% didn't receive a meaningful explanation about their family members condition); the positive impact of compassionate leadership (176 (75.2%) perceived their family member died in the 'right' place); and unmet emotional needs (30.1% rated emotional support as 'poor'). Being a male respondent (OR 2.9, p=0.03) and being able to visit during the last days of life (OR 2.2, p=0.04) were independently associated with good perceptions of support.

Conclusion: Promoting individualised care within an environment of public health restrictions can be enabled by proactive, regular, informative communication; local autonomy and decision-making; and facilitating the ability to be present before death.

Abstract number: R-20
Abstract type: Poster

Experiences, Challenges and Solutions in Specialised Inpatient Palliative Care in Germany during COVID-19 Pandemic – A Mixed-methods Analysis

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Background: In Germany the organisational challenges on the impact of the Corona pandemic on palliative care of patients with or without COVID-19 are diverse.
Aims: The study captures the experiences, challenges and solutions of health care professionals (HCPs) in specialist inpatient palliative care services. All results contribute to a development and consensus of a national strategy for palliative care in pandemic crisis.
Methods: Twelve guided expert interviews were conducted with HCPs in leading positions of specialist inpatient palliative care services. All interviews were analysed following inductive and deductive thematic coding. Based on these results a nationwide online survey of palliative care units (PCU), hospital palliative care support teams (PCST) and inpatient hospices (IH) was conducted.
Results: The response rate of the online full survey (n=623) was 39%. Experts described that therapeutic options were discontinued in the first wave (W1), while PCU tried to continue as many options as possible during the second wave (W2). PCU/PCST stopped or limited hospital admissions (W1 80% of services, W2 63%). Reported IH admission stops increased from 9% to 17%. Infected staff was reported by 45% of PCU/PCTS and 60% of IH (W2) These data show major disturbances on the organisational level in the pandemic. The quality of palliative care for patients in need has deteriorated according to 35% (W2) of online respondents.
Conclusion: The study provides important evidence about the deep impact from Covid-19 on providers of specailist palliative care. There is an urgent ethical mandate to maintain palliative care for everyone, and teams have to be strengthened to provide that care. The study is funded by the German Federal Ministry for Education and Research.

Abstract number: R-21
Abstract type: Poster

Health Care Providers' Experiences with Establishing Goals of Care for Patients with COVID-19

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Background: Exploring patients' goals of care (GOC) is integral to palliative care practice. COVID-19 may present new challenges to establishing GOC.
Aim: To describe the experiences and reflections of physicians regarding exploring GOC for patients with COVID-19.
Methods: Semi-structured interviews were conducted with physicians about their experience assessing GOC for patients with COVID-19. Thematic analysis was used to describe and interpret over-arching themes.
Results: Twenty-three physicians (12 Palliative Care, 5 Internal Medicine, and 6 Critical Care) were interviewed. Interim analysis of 16 coded interviews revealed 4 thematic categories of factors influencing establishment of GOC: resource availability, COVID-19 factors, patients' baseline health, and unusual communication challenges between health care providers and substitute decision makers (SDMs) or patients. Resource-related factors included impact of ICU/ventilator availability and personal protective equipment (PPE) shortages on GOC discussions. COVID-19 factors affecting GOC conversations included physician uncertainty of the course of illness; lack of definitive, evidence-based treatment; patient and family preconceived ideas about COVID-19; and risk of rapid decline. Factors associated with patients' baseline health included comorbid disease and ability to treat comorbid disease in parallel with COVID-19. Unusual communication challenges impacting GOC discussions included a high level of SDM involvement for GOC conversations, visitor policies potentially limiting SDMs' illness understanding, and virtual discussions or discussions taking place under layers of PPE creating barriers to effective communication between physicians, patients, and SDMs.
Conclusion: Preliminary analysis highlights the unique challenges faced by both health care providers and patients/SDMs to facilitate and participate in GOC conversations in the context of the COVID-19 pandemic.

Abstract number: R-22
Abstract type: Poster

Assessing the Response of Community Out-of-Hours Hospice Services in a Pandemic

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Background: The Coronavirus Disease 2019 (COVID-19) pandemic has caused unprecedented disruption to the delivery and usage of healthcare services worldwide. Given that most people spend their last year of life at home, the delivery of out-of-hours (OOH) care is vital, yet little is known about such care.
Aim: To examine the response to, and impact of, the COVID-19 pandemic on community OOH hospice services.
Method: An online questionnaire, containing open and closed questions, was circulated by email to 150 managers of UK adult hospices providing OOH palliative care in October 2020. Questions, adapted from COVPALL (Higginson et al. 2020), concerned service configuration, patient referral and staffing. Descriptive analysis was undertaken with quantitative and qualitative data.
Results: 47/150 responses contained COVID-19 data. All of these hospices had experienced COVID-19 cases among patients and staff. Several had rapidly implemented changes such as redeployment of staff (n=7), developed new services or expanded existing services (n=11), and risk assessment for COVID-19 among staff and patients (n=12).
Whilst hospices reported that they were responsive and flexible to patient and family needs; staffing issues (n=21) and procurement/use of personal protective equipment (n=17) posed considerable challenges to service delivery.
Conclusion / Discussion: The COVID-19 pandemic has resulted in a reactive response from hospices to ensure the continued delivery of OOH services, the implications of which are unknown. However, such rapid change highlights opportunities to review and redesign how OOH palliative care is delivered.

Abstract number: R-23
Abstract type: Poster

Experiences of End of Life Care and Dignity of Dying during the first COVID-19 Wave in the Netherlands, an Interview Study among Bereaved Relatives (Co-Live Study)

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Background: The COVID-19 crisis affected the care for critically ill patients, with or without a COVID-19 infection, and may have affected the experience of dying for them and their relatives at the physical, psychological, social and spiritual domains.

Aim: To get in-depth insight in the experienced (un)dignity of end-of-life care during the first wave of the COVID-19 outbreak in the Netherlands.
Methods: A qualitative study involving 26 in-depth interviews with bereaved relatives, nested in an online survey among 370 bereaved relatives of patients who died between March and July 2020 in the Netherlands. We analysed 'matters of concern' and formulated a dignity framework for analysis based on the models of Chochinov and Van Gennip.
Results: Bereaved relatives felt that dignity of their dying relative was undermined at three levels:

- Personal, by the fear of becoming infected, dealing with an unknown virus, insufficient medical treatment, witnessing their relative suffocate, being isolated or cut-off, feeling powerless, having to make decisions that lack humaneness or being kept out of the decision making.
- Relational, by diminished contact, not being able to comfort or care for the relative, limited possibilities of or support with telephone or video contact, not being able to say farewell, lack of attentiveness from and contact with health care professionals, tactless communication.
- Social /organizational, by lacking protective resources, care staff having limited time, unclear isolation policies and restrictive visiting rules.

Discussion and reflection: Various circumstances affected the dignity of end-of-life care during the first wave of the COVID-19 pandemic. Among which factors associated with the virus and the general context of the pandemic, and factors arising from preventive measures. Bereaved relatives experienced that preventive measures, based in human action, seemed alterable or could be softened by the health care professionals.
Funding: ZonMw

Abstract number: R-24
Abstract type: Poster

COVID-19: Addressing the Needs of Palliative and Hospice Patients by Pandemic Response Teams of Health Facilities - Preliminary Results of the PallPan Project.

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Background: To cope with COVID-19 health on facility and welfare organisation level, care facilities convened pandemic response teams (PRT). Pandemic measures restricted usual care efforts for patients with and without SARS-CoV2 in their end of life. The German PallPan-consortium investigates palliative care aspects during the pandemic.
Aim: To examine SARS-CoV2 PRT in Germany in terms of their experiences of end-of-life care problems, solutions and challenges.
Methods: Semi-structured qualitative expert video/telephone-interviews with members of health care facility PRT (10/2020-2/2021) and structured content analyses of the interviews.
Results: 21 interviews on 22 PRT (15 facilities and 7 welfare organisations) were analysed. Of the participants (33-68 y; 28.6% female) 76.2% were health care professionals or administrative staff and others (23.8%). 15 organisations provided specialized palliative care services. Main issues, the PRT reacted to, were organisational (e.g. hygiene material procurement, personal capacities, local pandemic plans), structural (e.g. preparedness for high incidences), informational (e.g. structure and share a multitude of sometimes contradictory information) and patient-related. Active measures on frequent end-of-life care issues such as social contact restrictions, family carers and team members' burdens and worries were reported for 13 PRT. Their reactions included recommending individual decision-making, enabling and inducing creative alternatives to routines, e.g. saying goodbyes outdoor. Decisions with ethical impact such as isolation measures in long-term care facilities and conflicting priorities on SARS-CoV2 protection and patients' quality of life and care challenged the PRT.
Conclusion: The results indicate that needs of patients in end-of-life care were subordinate to other challenges. Further results of the ongoing analysis on public administration level will be presented.
Funding: Ministry for Education and Research (BMBF)

Abstract number: R-25
Abstract type: Poster

Targeted Specialist Palliative Care Response to Respiratory High Care Unit during the COVID-19 Pandemic in an NHS Teaching Hospital

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Background: The second wave of COVID 19 resulted in an influx of patients in respiratory distress requiring non-invasive ventilation (NIV) support on the extended respiratory high care ward (RHC). Mortality rates were high, as was symptom burden at the end of life, resulting in an increased need for specialist palliative care support.
Aims: To provide early and proactive SPCT (supportive and palliative care team) intervention, in order to optimise symptom control in patients requiring NIV preceding or at the time of death. In particular to reduce the incidence of symptom crises due to respiratory distress. A secondary aim was to support ward staff in managing the clinical and emotional aspects of their work.
Methods: From December 2020 to February 2021 the SPCT redesigned their current service provision to allow a nurse specialist and/ or a senior doctor to attend daily board rounds on the 32 bedded RHC ward. Potential patients were identified for referral based on clinical judgement and a prompt question of 'would this patient benefit from early palliative care'.
Results: On average the team spent 3 hours/day on the unit. Over an 11 week period a total of 49 patients were identified for review. 73% of patients had a Covid positive or Covid pneumonitis diagnosis. 53% were on a form of respiratory support, either NIV or nasal high flow oxygen (NHFO). 63% of referrals died on the unit during this period, 59% had anticipatory subcutaneous medications prescribed and 49% had a continuous subcutaneous infusion prescribed by the SPCT. During this time period the SPCT were involved in the care of 72% of all patients who died on the unit.
Conclusion: Targeted integration of SPCT facilitated early referral. SPCT intervention resulted in appropriate symptom control prescriptions and reduced the numbers of urgent referrals for crisis management. RHC staff reported feeling better supported in the challenge of providing care.

Abstract number: R-26
Abstract type: Poster

The Impact of the Covid-19 Pandemic on Specialist Palliative Home Care. An Online Survey on Experiences of Involved Professionals

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Background: Professionals in specialist palliative home care face the challenge to adapt their working methods to the framework conditions required by the Covid-19 pandemic. Namely the stricter regulations in terms of hygiene and the restrictions on contact and visitation possibilities influence their central field of activity.
Aim: In order to improve the preparation of specialist palliative home care with regard to coming pandemics, the following questions are of central interest:

- What effect does the Covid-19 pandemic have on the care for critically ill and dying patients from a „specialist palliative home care"-point-of-view?
- Which solution approaches were developed?

Methods: With the help of a newly developed online questionnaire based on the based on the results of focus groups, a Germany-wide recruitment of specialist palliative home care teams was carried out. The online survey was conducted between Oct. 2020 and Jan. 2021. IBM SPSS 26.0 software is used to analyse the data collected
Results: 154 teams took part in this online survey. This represents a response rate of 43%. 55.4% of the teams have cared for patients infected with SARS-CoV-2. 41% reported an increase in number of patients, 43.2% state that their everyday work changed. One example is the increase in telephone consultations. Nevertheless, 62% of the teams report that they have been able to provide patient care and symptom management as well as usual. One possible solution mentioned was the establishment of home office.
Conclusion: The work of professionals in specialist palliative home care is affected strongly by the Covid-19 pandemic. The systematic recording of their experiences can have a positive impact on the care for critically ill and dying patients in times of a pandemic.
Funding: This research project is part of the project "Palliative Care in Pandemics" (PallPan) within the Network of University Medicine (NUM), funded by the German Ministry of Education and Research.

Abstract number: R-27
Abstract type: Poster

Teleconsultation for Specialist Palliative Care (PC) Services Integrating the Patient Reported Outcome Measure from a Low Middle Income (LMIC) Setting during COVID-19

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Background: Access to specialist palliative care can be limited in rural and remote areas especially in LMIC countries.This is amplified during COVID-19 Pandemic as most of the doctors are called to the frontline. Tele-consultation services can be used to overcome this barrier and provide individualised clinical care for patients in different geographical areas.
Aim: We describe the process of initiation of tele-consultation services and the initial results of the ease of using patient reported outcome measures remotely in a district in India.
Design: Community PC nurses identified patients needing a specialist medical advice,recorded details in a password protected document accessed by specialists remotely. The patients were then called through video call for detailed assessment including patient reported outcome measures and recorded electronically. Clinical advice was recorded and tele prescription created.Follow up care was done by the community nurse.
Results: We present the result over a period from October to February 2021 in a single consultant led service. Out of 68 patients with median age 68.5 (12-96), 56% were male, 57% had a non-cancer diagnosis of which 34% had CVA and 11% paraplegia. 57% were in stable phase of illness, 72% had AKPS $<$ 50%. Among IPOS symptoms weakness (72%) and poor mobility (78%) were common followed by pain (65%) and dyspnoea (40%). 26% were anxious and 28% depressed. 40% reported having adequate information. 28% had insomnia which was recorded as other symptom. 79% had no practical problems reported. IPOS peacefulness(40%) and sharing feelings (37%) were difficult to assess virtually.
Conclusion: Patient reported outcome measures can be integrated as a useful tool for clinical assessment through tele-consultation enabling better identification of unrecognised symptoms and enabling targeted clinical care. Further research is planned to evaluate the person-level outcomes and the effectiveness of remote service.
Funding: Self-Funded

Abstract number: R-28
Abstract type: Poster

COVID-19 Palliative and End of Life Care Plan (COPE-CP): Development and Audit of Outcomes

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Background and aim: Palliative care (PC) referral in serious COVID-19 patients improves decision-making, optimal health resource utilization, end-of-life symptom management, and family support. Development of a systematic decision-making matrix for PC referral for serious COVID-19 patients and an audit of its outcomes were explored in this study.
Methods:
Phase 1: A decision-making matrix for PC referral along with algorithms for managing symptoms and psychosocial needs of serious COVID-19 patients and their families were developed.
Phase 2: Audit of outcomes of PC referral in hospitalized serious COVID-19 patients was conducted using a pre-designed proforma. Disease demographics, illness variables, symptom management needs, and end-of-life care preferences were recorded and analyzed.
Results: Out of 1575 COVID-19 inpatients, 50 (3.1%) were referred to palliative care. Among 190 COVID-19 related hospital deaths, 20% (38) received end-of-life care. 88% were referred from ICUs, with 84% having $>$2 comorbid conditions. The median length of hospital stay was 14 days; the median duration between PC referral and death was 4 days. Among those who died with serious COVID-19 illness, PC referral had no impact on the duration of hospital and ICU stay.
Among the 50 referred for PC, 47 (94%) were referred for goals of care discussion. 78% received opioids, 70% benzodiazepines, and 42% haloperidol for symptom management. 48 (96%) families participated in PC family meetings for documentation of end-of-life care preferences and 31 (62%) opted for limitation of life-sustaining treatment. 31 (62%) patients died in the ICU, while 7 (14%) died in the palliative medicine high-dependency unit. Psychosocial and bereavement support was offered to all.
Conclusion: COPE-CP was accepted and implemented in the COVID ICU. PC referral enabled access to management of end-of-life symptoms and facilitated limitation of life-sustaining treatment in serious COVID-19 patients.

Abstract number: R-29
Abstract type: Poster

Ensuring Primary Palliative Care for Patients with/without COVID-19 during COVID-19 Pandemic – GPs' Experiences, Challenges and Perspectives

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Background: The SARS-CoV-2 pandemic poses major challenges for the health care system. While the infection protection and medical care provision for those infected is the primary intention, it is equally important to maintain and ensure the continuation of palliative care.
Aim: The study examines general practitioners' (GPs) experiences, challenges and perspectives on the provision of care for seriously ill and dying patients (with/without COVID-19) and their relatives in pandemic times in Germany.
Methods: In 2020, a standardized questionnaire was developed based on findings from an online focus group and two telephone interviews with GPs. The link to the online survey was spread via different email distribution lists (e.g. university institutes for general practice, medical associations; snowball system) to GPs nationwide. The survey was open for four weeks. The questionnaire mainly uses verbal rating scales which were analysed using descriptive SPSS tools. Free-text comments were analyzed based on Kuckartz content analytical methodology using MAXQDA.
Results: 410 GPs participated in the survey. GPs noticed a major challenge with contact restrictions which caused deterioration in physical and mental health of patients at their homes (43%; 77%) and in nursing facilities (53%; 89%). Telephone contacts with patients and relatives had increased compared to before the pandemic (63%). One third of GPs offered video consultations. GPs rated the cooperation with other healthcare providers from good to adequate during pandemic times. Among other stresses, GPs observed an increased fear of loneliness in patients. They also showed an increased personal stress. The integration of GPs in pandemic task forces (92%) was recommended.
Discussion: The present work provides insights into pandemic crise management of GPs and supports the development of a national strategy for palliative care in pandemic times.
Source of funding: Federal Ministry of Education and Research (BMBF 01KX2021)

Abstract number: R-30
Abstract type: Poster

Interdisciplinary Palliative Care during the First SARS-Cov-2 Pandemic Phase in German Hospitals

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Background: The SARS-CoV-2 pandemic challenged interdisciplinary cooperation between hospital staff and specialized palliative care (SPC) by facing sudden restrictions, yet dying patients still required comprehensive palliative care.
Aim: Examination of interdisciplinary cooperation from the point of generalist palliative care between hospital staff and SPC during the SARS-CoV-2 pandemic in German hospitals as a part of a multicenter project (PallPan).
Method: A 43-Items-questionnaire was developed based on literature and semi-structured qualitative interviews concerning the first pandemic phase and was sent to hospital staff via the online platform UniPark (n=10.357). Excluded were inhospital specialized palliative care. Interviewees were able to answer the questions beginning from 01/12/20 until 20/01/21. The data was analyzed via SPSS and descriptive statistics and cross tables were done.
Results: In total 550 hospital staff did answer the questionnaire and after exclusion of SPC-respondents 530 questionnaires were analyzed. While 32.4% (n=159) did not have the possibility to include SPC into the care process, 74.1% (n=215) did often incorporate SPC in their daily work. There was a significant discrepancy for SPC-co-management regarding Covid-19 positive (46.6%, n=152) and Covid-19 negative patients (69.9%, n=228, $p= < .001$). Most hospital staff considered additional support by SPC as helpful (83.1%, n=368). This contains mainly easily accessible information (69.0%, n=254) and training in palliative care (63.9%, n=235).
Discussion: Inhospital SPC was present in the pandemic, yet there is space for improvement. The discrepancy concerning SPC-co-management at the patients' bed is one major issue that needs to be addressed. In order for a comprehensive care SPC should provide training and easily accessible information to generalist palliative care during and outside a pandemic.
Main source of funding: Federal Ministry of Education and Research

Abstract number: R-31
Abstract type: Poster

Palliative Care in Resource-poor Settings – Identifying the Ethical Questions and Challenges Faced during a Global Pandemic

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Background: As the COVID-19 pandemic evolves healthcare organizations in the UK, US, and Europe have called for greater access to palliative care. This call has been echoed by palliative care practitioners in the low- and middle-income countries (LMICs). While the need for palliative care may be universal, there are cultural and resource differences between the high-income countries where palliative care and its ethical principles was first developed and the LMICs. These differences may have an impact on the application of ethical principles to palliative care which could hamper efforts to deliver palliative care in areas where the need is greatest. Many key challenges to the delivery of palliative care in LMICs, particularly during public health emergencies, remain unaddressed and in some cases, unidentified.
Aims: To review the literature on the delivery of palliative care in public health emergencies and the COVID-19 pandemic. We sought to identify key challenges and questions on how LMICs should deliver culturally sensitive, ethically acceptable palliative care at scale.
Approach taken: We conducted a search of the recent literature on the challenges of delivering palliative care in public health emergencies such as the COVID-19 pandemic. Our analysis grouped the challenges according to emergent themes. We then defined questions with which to interrogate each theme, and the components that must be investigated to answer the questions.
Results: Four challenge themes and defining questions to be addressed were identified.

Challenge themes	Defining questions	Components for investigation
Palliative care across different cultures and societies	How can the ethical principles and the delivery of palliative care be adapted in different cultures to ensure acceptability, relevance, and collaboration with local communities?	Differences in palliative care ethics and principles in different cultures and societies Factors for success in delivering palliative care across different cultures and societies
Palliative care in resource-constrained settings	How do we maintain adherence to the ethical principles and aims of palliative care, when faced with varying degrees of resource constraints?	The real-world ethical dilemmas of providing palliative care in resource-constrained settings Physical, psychological, social, and spiritual suffering - how can palliative care address them all with limited resources? Is there a human right to palliative care?
Health resource allocation and the role of palliative care	How can triaging, healthcare rationing, and advance care planning be done ethically in resource-constrained settings?	Avoiding discrimination and bias in triaging, resource allocation, and advance care planning Palliative care as a resource-conserving measure or a cheaper alternative to appropriate curative care
Health systems performance for palliative care in public health emergencies	How should the quality, outcomes, and standards of palliative care delivery during public health emergencies be monitored and measured?	Goals of palliative care in public health emergencies Applying palliative care quality measures and standards to public health emergency settings

Conclusion: To deliver palliative care successfully during public health emergencies in resource-poor settings, several questions have to be considered. Answering these questions will require targeted research and discussion across disciplines and around the world.

Funding: This study was funded by the World Health Organization.

Abstract number: R-32
Abstract type: Poster

Mentoring in Palliative Medicine in the Time of COVID-19

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Background and aim: The COVID-19 pandemic has had significant ramifications upon clinical medical education. Restrictions on in-person face-to-face meetings and the limited mentoring support from redeployed physicians have compromised mentoring relationships and jeopardised mentoring programs in palliative medicine. The evidenced success of combined novice, peer-, near-peer and electronic-mentoring (CNEP) and interprofessional mentoring (IPM), together with palliative medicine's emphasis on interprofessional teamwork for holistic patient care, suggest that the concurrent application of CNEP and IPM (CNEP-IPM) may be effective in addressing the continued geographical and manpower constraints in palliative medicine training amidst the COVID-19 pandemic. This study thus aims to assess the viability and suitability of a CNEP-IPM mentoring approach in palliative medicine.

Methods: With little known about this form of mentoring, a systematic scoping review (SSR) was carried out studying published accounts of CNEP and IPM. The Systematic Evidence Based Approach (SEBA) was adopted to enhance the trustworthiness, transparency and reproducibility of SSRs.

Results: A total of 15,121 abstracts were reviewed, 557 full text articles were evaluated, and 92 articles were included. Concurrent content and thematic analysis revealed 4 themes/categories: characteristics of CNEP and IPM, stages of CNEP and IPM, the roles of host organizations and assessment methods and criteria.

Conclusions: This SSR evidences the viability of a CNEP-IPM approach and forwards an evidence-based framework for the design, implementation and evaluation of a CNEP-IPM mentoring program in palliative medicine. Further prospective studies and research into the program design, mentoring process, complex CNEP-IPM mentoring relationships, and the validation of robust evaluation tools are still required.

Abstract number: R-33
Abstract type: Poster

Nationwide Strategies Employed to Provide and Integrate Palliative Care to Patients with COVID-19

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Background: Little is known on what palliative care (PC) has been provided to patients with COVID-19.

Aims: To understand what PC was provided nationwide to patients with COVID-19 and strategies implemented to overcome barriers during the pandemic.

Methods: Semi-structured interviews were conducted with physicians across Canada about their experiences providing PC to patients with COVID-19. Thematic analysis was used to describe and interpret overarching themes.

Results: Twelve specialized PC (SPC) and 11 primary PC (PPC) were interviewed. Interim analysis of 16 coded interviews demonstrated SPC and PPC physicians used traditional strategies (such as opioids, oxygen and serious illness conversations) to manage symptoms, support end of life, and engage patients and families in goals of care conversations (GOC). Neither SPC nor PPC indicated strong adoption of GOC and symptom management tools circulated early in the pandemic. Both SPC and PPC indicated a shift to virtual communication due to restrictive visitor policies, highlighting the need for distanced support and planned communication. Care coordination for PC patients was challenged by a lack of community resources, family infected with COVID-19, prolonged hospital stays, and increased number of PC patients discharged to rehabilitation services.

New PC structures included; GOC teams that functioned in the emergency department and medicine floors, integrated clinical rounding by non-PC clinicians with PC teams, and hospital-based PC outreach to long term care. Strategies to improve PC implementation included: virtual technologies, team collaboration, patient and family engagement tools, and symptom management and GOC conversations tools.

Conclusions: While PC management approaches to support patients with COVID-19 were mostly unchanged, new structures and strategies were developed to ensure patients and their families were provided with support.

Abstract number: R-34
Abstract type: Poster

The Ad Hoc Establishment of an Acute Palliative Care (PC) Ward for Covid-19 Patients in a Tertiary University Hospital in Germany – The Perspective of the Staff and Stakeholders Involved

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Background: Due to the steep increase of Covid-19 cases in March 2020, we established a PC ward for dying Covid-19 patients to support emergency/intensive care medicine in the event of capacity shortages and to create a dignified PC. The station was up and running within 3 days, with both PC team members and volunteer nurses from non-palliative care units working together.
Aims: To explore: How did staff and stakeholders experience the ward's ad hoc implementation? What are the lessons learned?
Methods: A qualitative study was conducted (May-November 2020). 29 semi-structured interviews were led with PC staff, voluntarily enlisted staff and management, transcribed verbatim and a qualitative content analysis was performed.
Results: Patient care and team collaboration were rated positively. Whereas the volunteers had the role of open-minded learners, the PC staff was considered as experts in end-of-life care and approachable instructors.
The joint induction training proved to be central. This included a kick-off meeting and equipment training, the familiarization with the ward, training at the patient's bedside by the PC team as well as the support of the nursing/medical management.
Named challenges were yet: On the volunteer side an adaption to PC routines and a different culture of care; balancing the high standards of PC against the backdrop of pandemic conditions on the PC team side.
Also, criticism was levelled at the rapid opening of the ward as sufficient capacities at the other Covid-19 stations led to a low occupancy of the ward, staff overcrowding and frustration.
Conclusion: Our study shows the possibility to establish an ad hoc acute PC unit, where PC staff in a short time can successfully train volunteers. Nevertheless, due to the unpredictable dynamics of a pandemic, management and staff should be prepared for both scenarios: a low as well as a high occupancy of the station and the burden that comes along with each challenge.
Funding: MWFK Baden-Wuerttemberg

Abstract number: R-35
Abstract type: Poster

Evaluation of the Faculty Experience in Developing and Delivering Palliative Care e-resource Toolkit for COVID-19 for Low and Middle Income Countries (LMICs)

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Background: Integrated palliative care through equipped health care workers is essential in supporting those affected by the global COVID-19 pandemic. We developed & disseminated a Palliative Care in COVID-19 Resource Toolkit for LMICs focussing on those affected by co-morbidities & comprising an e-book, webinars x5, ECHO platform interactive sessions for HCW. Core competencies were ethics & goals of care, communication, self-care, symptom control, end of life care, bereavement & making sense of distress. To date delivery of 26 courses to >1200 participants in 15 countries. Quantitative data from participants show impact on all areas of competence.
Objective: To evaluate the faculty experience in the development and delivery of the Resource Tool kit .
Methods: A google forms survey to all faculty rating their experience of preparation, planning & delivery + pre & post levels of confidence & knowledge.
Results: 19 faculty (95%), median age 51(29-63), 84% doctors, 10% nurses, 21% & 31% >20 years experience in PC & teaching respectively. 20% no prior experience of virtual teaching & 95% no experience of flipped classrooms. >90% agreed WhatsApp communication, co-facilitation & teaching methodology using flipped classrooms, algorithms & case narrative helpful.Faculty reported feeling valued, supported,engaged & a sense of solidarity and purpose. There was improvement in knowledge (pre 6.55 post 7.64) & confidence (pre 6.06 post 7.76) in teaching competency domains. 95% would recommend the Toolkit.
Conclusion: The experience of developing & delivering a novel online training package showed benefits for this experienced Faculty in developing knowledge & confidence as well as a sense of purpose & solidarity when working in isolation in the midst of a pandemic. Using novel teaching methods & co-facilitation with peer support offered learning relevant for future training. Further qualitative study planned to explore the impact for Faculty & Participants.
Funding: Self-funded

Abstract number: R-36
Abstract type: Poster

Pandemic Plans and their Considerations of Palliative Care Aspects in Germany

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Background: The effects of the COVID-19 pandemic are apparent in a special way in the palliative care of patients and their caregivers. The German PallPan-consortiums is analyzing nationwide palliative care aspects aiming at developing recommendations.
Aims: The objective of the study was to survey the consideration of palliative care aspects in current pandemic plans (PP) in Germany. The study started 11/2020 and data lock was 2/2021.
Methods: We performed an investigation by direct contacting of administrative facilities of all cities > 100.000 inhabitants) as well as the two most populated counties of each federal state of Germany via email. We searched for PP via the WWW and by direct contacting (telephone). Here, we report on preliminary results of an ongoing analyses of the contents of the PP.
Results: The PP for all 16 German federal states (GFS) and the national PP were openly accessible. In contrast, PP of the other levels were only available for analyses in a limited number due to limited open access or responses. Overall 37 PP (cities n=12, others n=9) were analyzed. Authors were mentioned in 83% and 67% respectively. In no case a palliative care expert was mentioned as an author. The tables of contents

were very heterogeneous including no palliative care sections. We then scanned for relevant contents in regards to palliative care i.a. by screening for words of interest. (e.g. "palliative", "dying"). Of note, none of the PP included the word "palliative".

Conclusions: Pandemic plans are difficult to access for the scientific community as well as others. Palliative care aspects have so far not been included in the German PP. Clear recommendations for dealing with seriously ill or dying patients and their families have to be developed and must be included in future PP.

This research is sponsored by Federal Ministry for Health (BMBF) and part of the joint project "PallPan - Nationale Strategie für Palliativversorgung in Pandemiezeiten".

Abstract number: R-37
Abstract type: Poster

Oncologists' Experiences, Challenges and Approaches Concerning Outpatient Care for Severely Ill and Dying Patients and Their Relatives in the COVID-19 Pandemic

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Background: In Germany as well as in other countries, resident oncologists are challenged by the current pandemic as they seek to ensure continuity of treatment and care for cancer patients in severe or terminal conditions with and without SARS-CoV2-infection.

Aim: The study aims to analyze challenges, experiences and emerging solutions of resident oncologists in Germany with regard to health care for patients with palliative oncological diseases and their relatives during the pandemic. The findings will contribute to a national strategy on palliative care in pandemic times.

Methods: 13 guideline-based telephone interviews with oncologist from Sep-Oct 2020 were analysed using a content-analytical approach. This study is part of the nationwide collaboration project "National Strategy for Palliative Care in Pandemic Times" (PallPan).

Results: At the onset of Covid-19 pandemic some patients have cancelled or postponed follow-up appointments due to fear of infection. Although it seems challenging to make up with those appointments, oncologists report having had no considerable loss of quality of care. In individual cases, patients were referred late from GP care to oncology and therapies started with avoidable delays.

Due to a lack of user competency and uncertainties about data protection, digital solutions such as video consultations were used rarely.

Practice teams had to re-structure practice facilities, working schedules and appointment management to stick to infection protection measures.

The network including other caregivers such as GPs and palliative care teams was assessed mainly stable and stress-resistant which contributed to good patient palliative care.

Discussion: The reported re-arrangements on facility level helped securing care and therapy provision and could be re-used in future pandemic times. Public health authorities at local, state and federal level must improve pandemic planning.

Source of funding: Federal Ministry of Education and Research (BMBF 01KX2021)

Abstract number: R-38
Abstract type: Poster

Between Equity and Dignity: An Argument-based Review of European Ethical Guidelines under COVID-19

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Background: At the beginning of the COVID-19 pandemic, many organizations developed guidelines to deal with the ethical aspects of resources allocation. The central question regards how to establish a fair resource allocation and how to guarantee that the decisions are made ethically and consistently. This study describes the results of an argument-based review of ethical guidelines developed by different institutional bodies at the European level.

Aims: The study aims to increase knowledge and awareness about the moral relevance of the outbreak, especially as regards the balance of equity and dignity in clinical practice and patient's care.

Method: We followed the model of McCullough et al. to perform an argument-based review. We started our research from the following two question: what are the ethical principles adopted by the ethical guidelines produced at the beginning of the COVID-19 outbreak regarding resource allocation? And what are the practical consequences in terms of 'priority' of access, access criteria, management of the decision-making process and patient care? Then, we performed a literature search, and finally, we identified, described and analyzed the ethical arguments in connection with the conceptual-ethical questions.

Results: Twenty-three ethical guidelines met our inclusion criteria. The results of our analysis are organized into 4 ethical concepts and related arguments: the equity principle and emerging ethical theories; triage criteria; respecting patient's dignity, and decision making and quality of care.

Conclusion: The European ethical guidelines are very sensitive to the risk of discrimination arising from strict triage criteria and figuring out a way to personalize care during COVID-19 still represents a moral duty. Further studies can investigate the practical consequences of the application of the guidelines described, in terms of quality of care and health care professionals' moral distress.

Abstract number: R-39
Abstract type: Poster

"Away from the Hug, Close to the Heart": Virtual Visits in COVID-19 Pandemic

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Background: The COVID-19 pandemic brings sudden changes in health care. During the period of social distance and restricted contact, it was necessary to restore the communication between inpatients and their relatives in the oncology setting. Even though we did not find publications about psychosocial virtual visits (VVs) in this context, these video interactions have emerged as an innovative and necessary alternative to support advanced cancer care patients (ACCP).

Aim: Identify and describe the implementation of psychosocial virtual visits used in an Oncology Institute.

Methods:

A quantitative, descriptive, exploratory study

Research question: What are the characteristics of virtual visits made with advanced cancer care patients?

Data Collection: a retrospective, consultation of clinical files, March to December 2020.

Non-probabilistic sample, random type.

Participants: ACCP over 18 years old.

Data analysis: Descriptive statistics software.

This study complied with the ethical norms.

Results: The psychosocial VVs directly benefited 707 persons, 145 patients (average age 70) and 562 (with emphasis on 519 relatives and 43 significant others). All visits were carried out by a psychosocial support team. The majority of VVs happened in the oncology service and in the PC services. Of all the patients who were integrated into VVs, 49 were PC service inpatient and 37 of whom died. The VVs allowed us to keep providing holistic care in an advanced disease context. Two brochures were developed related to good practices in VVs, which were disseminated nationwide.

Conclusion: The pandemic was a powerful motivator for systemic change and made professionals search for new ways to provide care and connection between patients and their relatives. Although technology does not replace face-to-face visits, it can offer meaningful interactions and contribute to the wellbeing of everyone involved. In the field of advanced disease, we continue to provide PCs to those who need them.

Abstract number: R-40
Abstract type: Poster

Perspectives on Care and Compassion Regarding the End of life under COVID-19 – An Online Survey within the Caring Community Cologne

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Background: In order to be able to ensure the quality of someone's life until the end, social participation and dignity are important aspects, as well as the public perception of preserving personality and identity. However, the COVID-19 pandemic caused strict visiting regulations in hospitals and nursing homes and therefore physical segregation of dying people.

Aims: To explore the people's perceipton of death-related issues before and during the pandemic.

Methods: After the first COVID-19 lockdown in Germany we conducted an online survey with citizens who were interested into participating in the Caring Community Cologne project. Respondents were asked to describe their views on dealing with death, mourning and dying before and during the pandemic. Free-text comments were analyzed using qualitative content analysis.

Results: 68 participants completed the survey. The majority of respondents were 50 to 70 years old (64 %) and female (65 %). Most of them worked in the social sector (43 %).

The most frequently mentioned aspects were:

- Non-professional care structures need to be strengthened, existing structures should be made visible and connected with each other. The end of life was brought into public view.
- The fear of social isolation for older and sick people and the inadequate support for the dying and their relatives lead to concerns.
- There is growing concern about a lack of human togetherness.
- The importance of caring for one another within an informal context increases.
- There is a greater need for the discussion of death-related topics.

Conclusion/discussion: The drastic changes during the pandemic seem to affect the views on institutionalized care as well as the perception and experience of social cohesion. In addition, individual needs on a local and interpersonal level as well as the confidence in and extent of their concerns about cohesion become apparent.

Abstract number: R-41
Abstract type: Poster

A Smile behind the Mask: A Systematic Review and Narrative Synthesis Exploring how Family Members of the Seriously Ill or Dying Supported and Cared for during Infectious Disease Outbreaks

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Background: Infection control measures during infectious disease outbreaks can have significant impacts on seriously ill and dying patients, their family, the patient-family connection, coping, grief and bereavement.

Aim: To explore how family members of patients who are seriously ill or who die during infectious disease outbreaks are supported and cared for during serious illness, before and after patient death, and the factors that influence family presence around the time of death.

Methods: A systematic review and narrative synthesis was undertaken. CINAHL, Medline, APA PsycInfo and Embase databases were searched from inception to June 2020. A forward and backward search of included papers was also undertaken. Records were independently assessed against inclusion criteria. Included papers were assessed for quality, but none were excluded.

Results: Key findings from the 14 included papers include the importance of communication and information sharing, including new ways of using virtual communication. Restrictive visiting practices were understood by family, but the impact of these restrictions on the family experience and patient-family connection cannot be underestimated, causing distress and suffering. Consistent communication and information were critical to supporting family members including explaining personal protective equipment, which family found constraining and staff believed affected interpersonal communication. Cultural expectations and obligations associated with family caregiving and death were challenged during infectious disease outbreaks.

Conclusion: Learning from previous infectious disease outbreaks about how family are supported is important and can be translated to the current COVID-19 pandemic and future infectious disease outbreaks. Consistent, culturally sensitive and tailored plans should be clearly communicated to family members, including when any restrictions may be amended or additional supports provided when someone is dying.

Abstract number: R-42
Abstract type: Poster

Impact of the Covid-19 Pandemic in Compassionate Care: A Descriptive Study

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Background: The Covid-19 pandemic has increased pressure on health systems, forcing professionals to make critical decisions in adverse environments. Combined with the fact that their patients often have no therapeutic options, healthcare workers are experiencing a consequent sense of failure.

Aims: To study compassionate care in palliative care professionals after the first wave of the pandemic in Spain.

Methods:

Design. Data were collected in May 2020.

Data collection. 57 professionals participated.

Analysis. Statistical analyses included descriptive information of COVID and compassionate care experiences.

Results: The majority of the participants were women (66.7%). Mean age was 46.15 years old (SD=10.75).

Most participants worked with Covid patients (n=35; 62.5%). When compared to professionals not working with Covid, they showed lowers levels of compassion satisfaction, positive self-compassion and well-being, and higher levels of burnout, compassion fatigue and negative self-compassion.

Among the professionals treating Covid patients, 28 had patients who had died. Only 13 affirmed the dying process had been accompanied by a family member, 9 believed they adequately accompanied their patients in the process, and 11 that it was a dignified death. Professionals feeling their Covid patients' deaths were dignified deaths showed higher levels of compassion satisfaction, positive self-compassion and well-being, and lower levels of burnout, compassion fatigue and negative self-compassion.

Conclusion: Although our results are mainly descriptive, because of the small sample size, they point out that palliative care professionals in the frontline of Covid-19 could suffer from problems of self-compassion, quality of life and well-being. This is even more likely in those who felt the patients' death were non-dignified deaths.

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Abstract number: R-43
Abstract type: Poster

The Experiences of Adolescents with Cancer during the COVID-19 Pandemic in Turkey

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Background: Adolescents with cancer have unique emotional needs. Their freedom in social and school life is usually limited. We aimed to investigate their experiences during COVID-19 in addition to their cancer.

Methods: Semi-structured interviews were conducted with 14 adolescents receiving chemotherapy.

Findings: They expressed their experiences in three dimensions. First dimension described their knowledge, attitude and practice relating to COVID-19. They thought it is highly dangerous to their immune system and ongoing precautions are not sufficient. Thus, they felt the need to isolate themselves not only in their home but also in their room. Personal experiences were second dimension with the following sub-themes: emotions, coping beliefs and expectations from the future. Most are afraid of becoming infected because of additional risks caused by COVID-19, believed that being in self-control protects themselves and thought that pandemic will influence their future distance toward others. Social experiences were the third dimension with the following sub-themes: attitude of the society, schooling and family and social relations. Some expressed their concern in relation to society's indifference toward vulnerable people, mentioned limited interactions with household and diminished friendship kept only through social media. For those who had postponed education or were home-schooling, COVID-19 made a positive impact by making them feel normal as their peers have to do same due to the lockdown.

Conclusion: Despite adolescents with cancer already knowing how-to live-in isolation, they still don't feel safe enough with the precautions and they perceived they need extreme isolation in comparison to general society during the pandemic. It is important to recognize these adolescents' need for extra safety and provide minimum conditions to enable them socialize during such crises.

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Abstract number: R-44
Abstract type: Poster

Palliative Care Consultation Team Activities during the COVID19 Pandemic: Differences between 1st and 2nd Wave in 2020-2021

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Background: In the Leiden University Medical Centre and Alrijne Hospital the palliative care consultation team (PCCT) is consulted for support in symptom management for COVID19 patients and communication with families.

Aim: To asses differences in patient characteristics and PCCT advise between COVID19 patients in the 1st and 2nd wave.

Methods: For all COVID19 patients admitted to the two hospitals for whom the PCCT was consulted, we prospectively registered patient characteristics, topics of advice and observed survival(OS). Differences between the two waves (1st 3–6/20; 2nd 9/20-2/21) were compared with chi-square and KM. At referral treating physicians were asked to estimate life expectancy. This was compared to OS (weighed Kappa (wK)).

Results: In 111 patients (55 1st, 56 2nd), 66% was male, median age 80 yrs. (range 42-99), 47% had a life-limiting illness before COVID19. There were no differences between 1st and 2nd wave except for performance (WHO 4: 50 vs 73%; p=.01). Main topics of advice were on dyspnea (80 vs 93%), palliative sedation (77% in both), medication (75 vs 64%) (all NS), and on social problems (25 vs 7%), existential problems (52 vs 29%), organization of care (36 vs 16%) (all $p < .05$). In the 2nd wave less extensive advice was given: symptoms mean number 1st 3,4 vs 2nd 2,7 (p.001), problems mean number 1st 4,4 vs 2nd 3,3 (p.002). 83% died in-hospital, 9% is still alive. After referral median OS was 1 day 1st vs 2 days 2nd wave (NS). In the 1st wave physicians estimated patients to live shorter (expected death within hours 1st in 31 vs 2nd 16% (NS). Estimated life expectancy was more correct in the 1st 60% (wK .36 (CI=.16-.56)) than 2nd 45% (wK .24 (CI=.04-.43).

Conclusions: In the 1st wave physicians referred COVID19 patients to the PCCT who were closer to death implying more awareness of deteriorating condition in the 2nd. When referred earlier, PCCTs can better aid in optimizing symptom management and end-of life decisions, and support families.

Abstract number: R-45
Abstract type: Poster

COVID-19 and Ethical Care at the End of Life: Using Qualitative Media Analysis to Understand Experiences of Care Home Residents with Dementia

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Background: A palliative care approach for people with dementia is imperative for care quality and ethical practice. COVID-19 has affected health outcomes for care home residents with dementia. Therefore, it is important to explore whether residents received end of life care consistent with ethical standards during the pandemic.

Aims: This study sought to understand the experiences of care home residents with dementia during the pandemic.

Methods: A review was conducted using approaches from qualitative media analysis, mapping news articles that reported care experiences from the frontline. Searches for articles took place at three time points within a specific time frame. Forty-seven articles were thematically analysed and coded.

Following this, salient ethical values for care delivery were identified by synthesising relevant UK ethical standards and codes of practice. These values were used to analyse real life experiences reported in the literature, and the extent to which ethical end of life care was evident during the pandemic.

Results: Findings identified experiences for care home residents with dementia relating to: caring; non-maleficence; beneficence; procedural justice; dignity in death and dying; wellbeing, safety; personhood.

The analysis showed positive experiences resulting from ethical practice displayed by care home staff, care organisations and the third sector. However, negative experiences for residents and staff were also evident, demonstrating the failings of negligent government strategy. Delayed guidance, lack of personal protective equipment, unclear data and inconsistent testing combined to undermine ethical care during the pandemic.

Conclusion: These findings have implications for other countries, highlighting ethical values to uphold at the end of life for people with dementia, and areas to be prioritised to maintain care quality.

Abstract number: R-46
Abstract type: Poster

Death, the Internet and COVID-19 - Insights from the Digital Death Survey

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Background: The Digital Death Survey explores society's attitudes and behaviours related to death and technology (the internet, social media, etc). This flagship survey was first carried out in 2014 and has helped academics, healthcare professionals and policy makers better understand these topics. The survey is conducted by the Digital Legacy Association (UK). This year the research received further support from Dr. Carla Sofka of Siena College (USA). The 2021 survey was reviewed and approved by the Siena College Institutional Review Board before being conducted (IRB #08-02-20).

Aims & goals: To understand how the internet, technology and COVID-19 is changing society and societal needs.

Methodology: Quantitate survey with supplementary quantitative questions. Data segmentation by age, professional /non-professional/ other demographic metrics.

Results: COVID-19 has increased the usage of online services. When asked; *"As a result of the COVID-19 pandemic, do you think that you are now more likely to document your end of life wishes?"* 30% stated "*Yes, I am more likely to document my wishes*". 40% of people had watched a virtual funeral since the start of the pandemic (funeral stream), 84% had shared a memory or a message online about someone who had died and 16% had participated in an online memorial / vigil.

Conclusion / lessons learned: The pandemic is rapidly changing peoples attitudes around planning for death. Attitudes and behaviours previously changing at a gradual amount have been accelerated due to the COVID-19 virus and social distancing measures.

Abstract number: R-47
Abstract type: Poster

End-of-Life Care, Dying and Bereavement during the COVID-19 Pandemic from Latin American Perspective

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The COVID-19 pandemic is a serious threat to public health. Latin American structural conditions are a propitious place for the spread of COVID-19. Argentina, Brazil, Chile, Colombia, Mexico and Peru are the countries with the most deaths on the continent.

We aimed to explore the characteristics of EoL care practices as provided during the pandemic in 7 Latin American countries (Argentina, Brasil, Chile, Colombia, El Salvador, Perú, Uruguay) and the experiences from relatives and healthcare providers.

Methods: Observational study of a convenience sample of people who have recently experienced the death of either a relative or a patient died or not from COVID-19 using 2 rounds of questionnaire surveys, with additional deep-interviews. Social Determinants of Health, working conditions, and QoL were assesed. Primary outcome: a descriptive assessment of the characteristics of EoL care during the pandemic, from the experience of relatives and HCP.

Preliminary Results:1430 questionnaires completed until now (726 relatives/704 HCP) In-depth interviews analysis in progress. Most of the relatives perceived their loved ones were treated with respect and dignity during the last days of life by doctors 85% and nurses 81 % most of time. HCP rated their QoL average 5 (1 Very poor, 7 Excellent).

Main Questions	**Quest 1 relatives (%)**	**Quest 2 relatives(%)**	**Quest HCP (%)**
There was enough medical care (Strongly agree + agree)	76	82	90
There was enough help available to meet his/her personal care needs (Strongly agree + agree)	68	78	78
Do you think that the treatment or care of your relative was limited due to the Corona crisis? (No)	69	–	78
Were visitors allowed during the last two days of his/her life? (Yes, with limitations)	57	50	71
How would you assess the overall level of emotional support given to you by the HCP? (Excellent+Good)	36	–	37
How would you assess the overall level of emotional support given to you by the HCP? (Excellent+Good)	67	–	–
Did the HCP provide sufficient emotional support to the patient and relatives? (Yes, definitely + Yes probably)	–	–	79

Conclusion: Provision of best person-centred care for dying patients requires understanding of cross-cultural experiences of dying and bereavement. We provided international and multidimensional perspectives of the impact of this unprecedented pandemic from 7 Latin American countries.

Abstract number: R-48
Abstract type: Poster

Integrated Home and Palliative Care: Beyond COVID-19

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Background: About 5-10% of patients who develop coronavirus disease need hospital care, even in the Intensive Care Unit, and also those who have passed the acute phase and may remain at home rather than hospitalized often continue to need home care, regardless of previous condition.
Aim: The COVID-19 pandemic is upsetting the living conditions of everyone and especially of those affected by chronic and advanced diseases who have special health needs. We worked to assist patients who needs home care or social needs or palliative care or blood transfusions at home and are in a condition of isolation or quarantine.
Methods: Our Associations have set up 4 dedicated palliative and home care teams in the Province of Ragusa involving: 2 Doctors, 5 Nurses and 6 Social Health Operators, provided with adequate Personal Protective Equipment (e.g. protective clothing, face shield and safety glasses, gloves, shoes, FFP2 / FFP3 masks); coordinated by 2 Operational Centers. Dedicated vans are used, with isolated areas for carrying out the dressing/undressing procedures. Procedures for sanitation are used and the disposal of special waste is guaranteed.
Results: From 17*th* November 2020 to 13*th* February 2021, the teams assisted 134 patients with 859 home interventions and took 748 hours excluding travel times and dressing/undressing procedures. Among the interventions were given: 378 pharmacological therapies; 100 personal care hygiene interventions and 20 blood transfusions.
Conclusion: The strengthening of palliative and home care services with these teams has allowed to ensure continuity of care for COVID-19 patients with urgent needs for home and palliative care and for whom hospitalization is no longer appropriate and thus freeing hospital resources. This experience also increased the synergy with General Practitioners (GPs) for the evaluation and clinical/care management of patients and support to family members for any shared care planning.

Abstract number: R-49
Abstract type: Poster

Did Organizational Models and Designs of End-of-Life Care in Burn Intensive Care Units Change during the COVID-19 Pandemic? Professionals' Views and Experiences

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Background: Burns are a global public health problem, accounting for around 300,000 deaths annually. 25% of patients aged 45-65 with severe burns die. Given the changing environment of the COVID-19 pandemic, health services, including burn intensive care units (BurnICUs), were redesigned to be most effective.
Aim: To explore organizational models and designs of end-of-life (EOL) care in BurnICUs during the COVID-19 pandemic.
Methods: Qualitative study using in-depth interviews. All 5 BurnICUs reference centres across Portugal were invited; 3 participated. 15 professionals (12 nurses; 3 physicians) were interviewed after the first wave of the pandemic (July-October 2020), until reaching theoretical saturation. Analysis: inductive thematic analysis.
Results: Five themes emerged and divided in sub-themes: (i) Risk of infection/sepsis and strict visiting procedures (flexibility, by-passing visiting restrictions; struggle with visiting restrictions; videoconferencing); (ii) Hampered consultation model (specialist consultation and interventions from other professionals were impeded); (iii) Difficulties in case management (physicians on call); (iv) Palliative care (PC) not included; and (v) BurnICUs were reorganized.
Discussion: Organization design refers to the way in which the building blocks of organizations are (re)arranged to improve effectiveness and adaptive capacity. Findings show that decisions were made to adapt BurnICUs both to the challenges and impact of the COVID-19 pandemic and to the needs of critically burned patients. Tasks, rules, procedures and communication channels were reorganized.
Conclusions: BurnICUs were redesigned as organizational needs changed during the COVID-19 pandemic. Despite strict visiting procedures, strategies were implemented to meet patients and families' needs at the EOL. As before the pandemic, palliative care was not involved in EOL care. Findings show the need to further explore PC involvement in EOL care in BurnICUs.

Abstract number: R-50
Abstract type: Poster

Review of DNACPR Orders within the Coordinate My Care (CMC) System during the First Wave of the Covid-19 Pandemic

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CMC is an NHS service to support urgent and advanced care planning for frail and palliative patients and patients with complex and life-limiting conditions. CMC's consent model ensures that no decisions about a patient's treatment - including 'Do Not Attempt Cardio-Pulmonary Resuscitation' (DNACPR) decisions - are made without the patient and, where appropriate, a loved one. We assess if there was a change in the way patients were consented and had DNACPR orders recorded during the first wave of Covid-19 by reviewing 107,614 published CMC care plans. Overall, 68% of care plans were created with the direct consent of the patient, 6% with the consent of and Lasting Power of Attorney (LPA) and 26% in the patient's best interest providing clear justifications for the decision. Although we observed an increase in patients added to CMC in the first wave of Covid-19, the consent pattern remained consistent with pre-Covid data. CPR decisions were added to 27,161 CMC care plans between March and September 2020, 15,898 (59%) of which were recorded with DNACPR decisions. Of these, 52% were recorded as having the mental capacity to discuss the decision (consistent with pre-Covid data) and 37% as not having the capacity to discuss. 29% were recorded for resuscitation, which is more than the same decision in pre-Covid-19 data (18%). During first wave of Covid-19, 90% of care plans show a clear yes/no CPR decision, compared to 88% Pre-Covid-19. Of the CMC care plans which included DNACPR during the first wave of pandemic and where no mental capacity was indicated, all provide supporting information on discussions with family/LPA. We conclude that, with the right systems in place, conversations about advance care planning took place and were recorded on CMC. Embedding personalised advanced care planning into the standard health care practice enables bespoke patient-centred care, even during the pandemic.

Abstract number: R-51
Abstract type: Poster

Preparedness to face the COVID-19 pandemic in palliative care services in the Asia-Pacific region: a rapid online survey

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Background: Palliative care improves COVID-19 patient management who are highly vulnerable and facing higher risk of dying. However, evidence regarding palliative care preparedness and response plans is limited in the Asia-Pacific region.
Aim: To evaluate the preparedness of palliative care services in the Asia-Pacific region to respond to the COVID-19 pandemic.
Method: An online cross-sectional survey was developed based on prior methodology guidance and the International Health Regulations. It was emailed to the Asia-Pacific Hospice and Palliative Care Network subscribers (n=1551) and organisational members (n=185) from 10th June to 1st July 2020. Descriptive analysis was used for reporting.
Results: Ninety-seven respondents completed the survey. Around half of services were hospital-based (n=47, 48%), and public-funded (n=46, 47%). Half of services reported to have confirmed cases (n=47, 49%). Staff perceived moderate stress of being infected by COVID-19 (median: median: 7 on a 1-10 scale). > 85% of respondents reported they had up-to-date contact list for staff and patients, however one-third revealed challenges to keep record of relatives (n=30, 31%) and patients visited in communities (n=29, 30%). Majority of services (60%) obtained adequate infection control resources except face mask. More than half had no guidance on Do Not Resuscitate orders (n=59, 66%) and bereavement care (n=44, 51%). One-third considered they had capacity to train non-palliative care specialists in using protocols.
Conclusion: Recommendations to strengthen the palliative care preparedness include: 1) improving the access to infection control materials such as face mask and hand disinfectants; 2) acquiring stress management protocols for staff when unavailable; 3) reinforcing the contact tracing system for relatives and patients visited in the community and 4) developing guidance on patient and family care before and after patients' deaths.

Abstract number: R-52
Abstract type: Poster

The COVID-19 Pandemic and Palliative Care Units: A Cross-sectional Survey of the Informational Needs of Caregivers

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Background: Visiting restrictions placed on palliative care units due to the COVID-19 pandemic have resulted in emotional and psychological distress to patients, their caregivers and families. However, the informational needs of caregivers during pandemic visiting restrictions have never been studied.
Aim: To identify the informational needs of caregivers of patients admitted to an end-of-life palliative care unit under COVID-19 visiting restrictions.
Methods: Nineteen caregivers of patients admitted to a single palliative care unit while under pandemic visiting restrictions were recruited. A cross-sectional telephone survey was performed, which examined the importance of different informational needs of caregivers and how well these needs were being met.
Results: Receiving information about hospital regulations/procedures, health updates about the patient, social support for the patient and how to communicate with the patient in light of visitor restrictions were "very important" to caregivers. In contrast, caregivers were "neutral" towards receiving information about accessing psychosocial/emotional support for the caregiver and religious/spiritual support for the patient. Qualitative data summaries provided a richer understanding of these quantitative rankings.
Conclusion: These findings will assist healthcare professionals in providing optimal informational support to caregivers during visitor restrictions in order to improve the growing psychological impact on this population.

Abstract number: R-53
Abstract type: Poster

The Clinical Practice of Palliative Sedation in Patients Dying from COVID-19

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Context: Clinical experts noted challenges in palliative sedation (PS) during the COVID-19 pandemic. Patients were rapidly deteriorating and the indications for starting PS seems to differ compared to other terminally ill patients. It is unclear to which extent available PS guidelines are useful for these COVID patients.
Objectives: To describe the clinical practice of PS (e.g. indications, sort and dosages of sedative medication) in patients dying from COVID-19, in comparison to the practice in patients without COVID.
Methods: Retrospective analysis of patient data from a Dutch tertiary medical centre was performed. The study period (August '19-December '20) was divided in months before and during the pandemic. Preliminary analysis was performed for the sample until July '20 (further analysis will follow). Charts of adult deceased patients were included when sedation was started during hospitalisation in the study period. Patients receiving PS at an intensive care unit were excluded.
Results: 119 patients (pts) received PS. In 53 pts (45%) of this sample hospitalization was during the pandemic while 20 pts (17%) had a COVID-19 infection. In 65% of pts with COVID-19 refractory dyspnoea was reported, compared to 31% the non-COVID group ($p < .05$). The median duration of PS was significant shorter in pts with COVID-19 infections (4.5 vs 9.0 hours, p 0.03). In most of these pts, midazolam was given as a single bolus (55 vs 26%, p 0.01), in contrast to the Non-COVID pts who mostly received continuous infusion (58 vs 45%, p 0.06).
Conclusion: PS in COVID-19 pts had different characteristics compared to PS in non-COVID pts. The short duration of PS and the use of boluses midazolam only indicates a more sudden and adhoc dying trajectory and may hamper timely palliative expert involvement and shared decision making. More research is needed to evaluate the

performance- and efficacy of PS at the patients comfort levels and quality of dying.

Abstract number: R-54
Abstract type: Poster

Perception of Dignity in Patients, Family Members and Healthcare Professionals during the COVID-19 Epidemic: A Qualitative Study Based on the Model of Dignity in the Terminally Ill

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Aim: The Model of Dignity in the terminally ill identifies three main dimensions around which patients can construct the perception of dignity: illness-related concerns, dignity-conserving repertoire and social dignity inventory. These domains subsume both physical, social and spiritual domains of suffering. During COVID-19, there were several obstacles in maintaining patient's dignity, i.e.: healthcare professionals (HCPs) wearing personal protective equipment; the nature of COVID-19 symptomatology; patient's isolation.

We evaluated the dignity perception of patients who have experienced COVID-19, their families, and HCPs.

Design: Qualitative, prospective study, conducted through semi-structured interviews including: 10 HCPs (5 doctors and 5 nurses) who have cared for patients with COVID-19, 10 patients who had COVID-19 and 10 of their family members. The interview explored: how patients and families cope with COVID-19 and their perception of dignity; and how HCPs perceived the patient's dignity and their families. A multi-disciplinary expert panel (one palliative doctor, one research doctor, one bioethicist and one psychologist) determined the scope of the interview, after reviewing the recent literature on the concept of dignity in the terminally ill patients. They conducted the interviews and thematic analysis of the transcribed verbatim. Content analysis was validated by two external researchers.

Results: Preliminary data on HCPs show that: patient's dignity can be influenced by resources and organizational problems; accessibility of care (principle of equality); and difficult communication issues. Moreover, HCPs highlight the importance of 'seeing' the patient as a whole person and convey 'peace' to patients. Final results regarding patients and family members will also be presented during the congress.

Conclusion: The results will highlight the strategies to improve the patients' care during the pandemic while preserving their dignity.

Abstract number: R-55
Abstract type: Poster

Experiences among Swedish Patients in Specialized Palliative Home Care and their Significant Others during the Covid-19 Pandemic

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Background: Several Covid-related issues have so far been investigated. The threat from the pandemic for patients with progressive life-limiting illness and their significant others has not been studied.

There has been no formal lock-down in Sweden, but restrictions have been proposed and recommended, building on high confidence in the official authorities and personal responsibility. Our purpose was to explore experiences and consequences of the ongoing Covid-19 pandemic for patients in specialized palliative home care and their significant others.

Method: The study has a qualitative design based on interviews with patients and their significant others. The interviews were recorded, transcribed verbatim and analysed descriptively.

Findings: In total, 36 interviews were performed (of which 22 with patients). The findings disclose increased isolation and fewer social encounters due to the pandemic. The impact on personal life was described as ranging from very moderate to a torture-like experience. Some interviewees related the isolation more to decreased strength and functional decline due to the underlying condition than to the pandemic. Generally, the patients received necessary support in daily life thanks to efforts by their significant others and several creative solutions. However, the joy and support of meeting family and friends in real life were sorely lacking.

Anxiety and fear of being infected with Covid-19 were voiced. The significant others described frustration over not being able to provide the usual support. Both patients and significant others reported having received sufficient, and often crucial, support from the palliative care service during the pandemic.

Conclusion: The covid-19 pandemic affected patients and significant others in a range from moderate to torture like. They often found creative solutions to manage their everyday life. The goal of palliative care to provide appropriate support has generally been maintained during the pandemic.

Abstract number: R-56
Abstract type: Poster

A Qualitative Study Comparing the Similarities and Differences in the Needs of Patients under Inpatient Hospice Care and their Families at the Time of the COVID-19 Pandemic

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Background: The COVID-19 pandemic has been a great threat to facilities providing inpatient care to chronically/terminally ill patients and elderly people. This unprecedented situation has called for radical and previously untried solutions, including restrictions and in some cases a complete ban on visiting inpatients, reductions in the number of staff, and measures to improve sanitary regimes.

Aim: The aim of this study was to compare the key needs of patients and their families, analyse potential differences in the new situation, to identify the consequences of the changes outlined above and to aid in the development of solutions adjusted to the new reality.

Methods: A qualitative study was conducted in one Polish inpatient hospice. The study, based on a questionnaire containing 17 open-ended questions, was conducted among patients (12) and their families (9) between 22*nd* April and 8*th* May 2020. An inductive thematic analysis was conducted on the text responses using a medical anthropological approach.

Results: The analysis provides a basis for identifying the key needs of both groups studied and highlights the differences between them. The basic need of patients was shown to be physical closeness, and for families, it was a need to control the care provided to their relatives.

Conclusions: The differences in needs influenced the preferred forms of communication, with patients preferring phone calls and families preferring videocalls. Based on the results of the questionnaires, COVID-19 was also observed to play different roles and vary in importance between patients and their families. The findings of the study are not exhaustive, and further in-depth research is needed to explore this area of interest.

Abstract number: R-57
Abstract type: Poster

The Role and Response of Care Homes to Palliative Care Needs in the COVID-19 Pandemic: A Systematic Review

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Background: The COVID-19 pandemic has resulted in high mortality in care homes. Little is known about provision of palliative and end of life care in care homes during the pandemic.
Aims: To explore how care homes responded to COVID-19 with regards to palliative and end of life care.
Methods: A systematic review of Medline, Embase, PsycINFO and Web of Science. Eligible papers focused on palliative care in care homes during the COVID-19 pandemic. Narrative analysis, with findings synthesised according to physical, social, psychological and spiritual domains of care.
Results: Out of 521 papers, a total of 21 papers were included in the final review. 15 papers included the physical aspect of palliative care specifically regarding symptom control and anticipatory prescribing. 10 papers explored psychological needs, particularly regarding mental health conditions. 13 papers discussed the social aspect such as visitor restrictions, advanced care planning and hospital transfers. 7 papers explored the spiritual aspect including anticipatory grief and bereavement care. Only 4 papers out of the 21 discussed all 4 aspects of palliative care.
Conclusion: Internationally, little research has focused on understanding provision of palliative and end of life care in care homes during COVID-19 pandemic. Most of the research published has focused on narrow areas of palliative care such as advanced care planning around future hospital transfers. More research is needed for provision of guidelines and policies to promote a holistic approach to palliative care in care homes during the pandemic.

Abstract number: R-59
Abstract type: Poster

Necessary Discussions: The Development of Online Resources to Support Advance Care Planning in Nursing Homes in a COVID-19 Context

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Aim or goal of the work: The Necessary Discussions project developed a COVID-centric advance care planning (ACP) online training resource for nursing homes, with the aim of improving resident care at the end of life during a COVID-19 outbreak. A bespoke website has been designed to deliver information to residents, family members and nursing home staff, with the aims of increasing awareness and understanding of advance care planning, and to support communication and shared decision-making.
Design, methods and approach taken: Development of the website took place between late 2020 and early 2021, and was informed by a rapid review of existing literature and support from members of the project's Expert Reference Group, comprised of practitioners, academics and public involvement representatives. Existing ACP resources were synthesised and tailored for COVID-19.
Results: The resulting website is accessible and engaging, offering a COVID-19 specific resource for advance care planning. Distinct modules provide information appropriate for care staff and family members. Supplementary videos were produced offering advice from experts in the field. Further reading and additional resources are linked to from the website, and there is a strategic emphasis on self-care alongside care provision.
Conclusion / lessons learned: This project demonstrates how to develop accessible information for care staff and family members in a COVID-19 context. The project also identifies effective methods of virtual team working and group collaboration during COVID-19.
This project is co-funded by the Economic and Social Research Council (ESRC) as part of the UK Research and Innovation's rapid response to COVID-19, and the Health and Social Care Research & Development Division (HSC R&D Division) of the Public Health Agency in Northern Ireland.

Abstract number: R-60
Abstract type: Poster

Cancer Patients with Covid19- in the Largest Anticancer Hospital of Athens, Greece; A Retrospective Study of a Single Center Experience

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Background: Cancer patients are regarded as a vulnerable group in the Coronavirus 2019 (COVID-19) pandemic. To date, the clinical characteristics of COVID-19-infected cancer patients remain largely unknown. Palliative care encompasses a holistic care, which addresses physical, psycho/social and spiritual needs. During the pandemic, these are affected to a great extent.
Aim: Retrospective study analyzing the clinical characteristics, psychosocial needs and outcomes of COVID-19-infected cancer patients.
Patients/methods: Medical records were reviewed retrospectively. 71 patients were identified. Clinical characteristics, needs and outcomes were summarized.
Results: Median age was 60.3 years (range: 22-84). 52 patients were male. Lung cancer [10 patients] and breast cancer [10 patients] were the most frequent, followed by gastrointestinal tumors [8]. 70.42% patients had comorbidities; 52.8% had arterial hypertension, hypertensive or ischemic heart disease.
42 patients [59.15%] had a mild COVID-19 disease and recovered (80% at home). 21 patients [29.57%] died with severe symptoms leading to pneumonia, and/or acute respiratory distress syndrome and sepsis. Patients with gastrointestinal tumors recovered. Only 2/10 female patients with breast cancer died; the cause of death was terminal cancer and died at home. On the contrary, 8/10 male patients with lung cancer died from COVID -19; they all had metastatic disease (stage IV), were under multimodality treatment.
Depression and anxiety were common findings (65%), even those who survived from COVID-19. All informal caregivers faced three types of barriers; social distancing, lack of communication and advanced-care planning, as well as inability to be with them, even at the end-of-life.

Conclusions: Male patients with extensive lung cancer, heavily pretreated are more likely to develop severe complications and die hospitalized from Covid-19. Palliative care can address needs such as psychosocial support and communication.

Abstract number: R-61
Abstract type: Poster

Service Adaptation and Case Series of 57 Patients with COVID-19 under the Specialist Palliative Care Team

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Aim: To study the demographics, symptoms and management of patients dying from COVID-19 and describe how one hospital palliative care team adapted during the first wave of the pandemic.
Method: Retrospective case series of 57 patients and service evaluation of a last days of life ward at one teaching hospital in the North of England between March and April 2020. The ward was created following closure of an elective orthopaedic ward and was staffed by redeployed surgical and medical staff. The ward was overseen by the palliative care team providing ward rounds 7 days per week and training of staff.
Results: 54 out of the 57 patients studied died on the last days of life ward.
The median age was 81, 56% of the patients on our caseload were male and 46% of patients lived in a care home prior to admission to hospital.
All of the patients in our study had at least one medical co-morbidity, the commonest (56%) being cardiovascular disease.
52 out of 54 patients who died and 1 patient who survived had symptoms. The commonest symptom experienced was breathlessness which was present in 66% of patients. 53% of patients displayed signs of agitation towards the end of their life and 41% had respiratory secretions. Symptoms were effectively managed with standard doses of medications including Opiates, Midazolam and Hyoscine Butylbromide with 41% of patients requiring medications to be delivered by syringe driver devices.
Conclusion: Patients dying from COVID-19 have symptoms that are amenable to medications widely used at the end of life.
The formation of the last days of life ward was seen as a success within the hospital and positively received by other medical specialities. It gave an increased presence of the speciality within the hospital and is influencing further development of the service.
This study did not receive any funding.

Abstract number: R-62
Abstract type: Poster

Describe Health Outcomes in Patients from a Palliative Care Program with Diagnosis of COVID-19

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Aim: Describe health outcomes in patients from palliative care program with confirmed diagnosis of COVID19.
Methods: Observational study retrospective of a cohort of patients from a palliative care program in Colombia. Patients over 18 years of age with suspected COVID19 admitted to emergency or hospitalization were included, during April 2020 to January 2021.Frequencies and percentages were used to describe the categorical variables, and median and interquartile range used for age variable.
Results: 503 pa tients from a palliative care program were admitted to emergency or hospitalization due to suspected diagnosis COVID19, which 42,1% (n=212) had a confirmed diagnosis. The median age was 81 years old (RIQ= 72 -86) and 51,9% (n=110) men. Diagnostic of palliative care were solid tumors 28,8% (n=61), frailty severe 22,2% (n=47), organ failure 21,2% (n=45), neurological diseases 15,1% (n=32), chronic obstructive pulmonary disease 7,5% (n=16) and hematological tumors 5,2% (n=11) Some patients were included in the program only with COVID diagnosis. In terms of health outcomes, 156 patients with confirmed diagnostic died, the mortality rate was 73,6% (IC 95%= 67,2 – 79,1). Of which 22,4% (n=34) died in a palliative care unit and 77,6% (n=118) in hospitalization of highly complex. The patients who did not die (n=56), continued management in home hospitalization 26,8% (n=15), palliative care unit 26,8% (n=15) and ambulatory 46,4% (n=26). In patients without COVID19, death occurred in 118 patients with a mortality rate 40,5% (IC95%= 35,0 – 46,3).
Conclusion: There was an increase in mortality in the program patient{s whit COVID19 compared to the discarted. Our palliative care program performs networked care, despite the above during the pandemic, patients with confirmed infection during the high spread phase, were inpatient to reduce the risk of home contagion. No information in literature was found on the impact on health outcomes of COVID19 in palliative care programs.

Abstract number: R-64
Abstract type: Poster

Do Professionals’ Palliative Care Needs Change during COVID-19 Pandemic? A Longitudinal before/after Qualitative Study

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Background: In Italy, Specialist Palliative Care Teams (SPCTs) have had an essential role during the COVID-19 Pandemic, most of all developing models of ‘shared care’ with non-specialist in Palliative Care. SPCTs contributed to physical symptom control and to psychological or spiritual support for patients, carers and health care professionals (HCPs), with a special focus on advance care planning.
Our SPCT, during the first epidemic wave of COVID-19, developed and implemented an intensive experiential training program for all HCPs of the Infectious Disease Department supporting them in clinical, decision-making and communication fields.
Aim of the study: This study aims to evaluate the changes of palliative care needs and patient management perceived by HCPs between the first (T1) and second wave (T2) of the COVID-19.
Population and methods: The intensive experiential training was addressed to HCPs (forty physicians and nurses) involved in T1 of COVID-19. The training included supervision of daily briefings, bedside consultations, brief lectures on palliative care topics (especially delirium and dyspnea), a booklet addressing the assessment and treatment of palliative care needs.
This is a qualitative longitudinal study. Semi-structured interviews were performed after T1 and T2 of COVID-19 exploring the changing palliative care needs perceived and the solutions approached. The results of the interviews have been analyzed through thematic analysis to identify any possible changes in meanings attributed to that phenomenon from T1 to T2.
Results: The interviews analyzed at T1 highlighted three main thematic areas:1.The professional’s unpreparedness for this emergency;2.The request to the SPCT for support and training in clinical, decision-making and communication fields;3.The positive feedback by HCPs about the collaboration with SPCT. The results of the analysis of the interviews after T2 and the meaning shift between T1 and T2 will be presented during the Congress.

Abstract number: R-65
Abstract type: Poster

A Case of Covid-19 Presenting with Insomnia, Progressing to Extreme Agitation at End of Life

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Background: Covid-19 patients at end of life (EoL) suffer predominantly from rapidly escalating dyspnoea and agitation. An unusual symptom of Covid-19 is isolated extreme overwhelming cerebral agitation and Helms et al,[1] report an observational series of 58 patients admitted to Intensive Care Unit with associated encephalopathy, prominent agitation and confusion.

Case presentation: Male 74 year old patient with end-stage leukaemia, admitted to hospital with mild flu like symptoms. Tested positive Covid-19.Hospitalised for two weeks, then discharged to a Nursing Home. Only symptom remained was insomnia, however this was impacting with increasing irritability in a previously calm man. The irritability escalated to extreme agitation, screaming out in deep distress. No headache or signs of meningism. Patient hospitalised, Palliative Medical phone advice requested. The agitation was not associated with dyspnoea, chest secretions or pain.

Management & outcomes: A continuous sub-cutaneous infusion (CSCI) was commenced with opioid and midazolam and symptoms did not settle with increasing doses. The patient's close relative was an Oncology Nurse Specialist and was the only visitor allowed on ward. The patient's extreme agitation was deeply distressing and on day 3 phenobarbitone was commenced and within hours the patient settled and slept for the first time in three weeks. Phenobarbitone was delivered via stat dose and CSCI. The following day the patient required a third CSCI with diclofenac for resistant hyperpyrexia not controlled on regular paracetamol. The patient remained comfortable and passed away a few days later.

Discussion: This isolated symptom appeared to present with extremely poor sleep for weeks, then escalating into extreme overwhelming agitation. At EoL this isolated symptom is an indication for use of Phenobarbitone, that renders sustained benefit.

Conclusion: For 'patients with reversibility' it may indicate earlier than usual need for ventilation.

Abstract number: R-66
Abstract type: Poster

Focus on Corneas Procurement in Hospice and Coration-style: Organs/Tissues Procurement in the Hospital during the Covid-19 Pandemic

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Background: COVID-19 pandemic impacted significantly on the Healthcare system, at any of its branches.

Aims: We hypothesized a negative influence of the pandemic on organ and tissue procurement through the whole 2020.

Methods: We analysed the data inherently to cornea procured by the Hospice in 2020, comparing them with the previous year; that was eased by the constant procurement monitoring carried on by Regional and Local Transplant Coordination. Furthermore, we extended the look on the procurement activity of the whole Hospital, regarding both DCD and DBD cases.

Results: The number of cornea donors procured by the Hospice in 2020 is almost the same of 2019 (44 donors in 2020; 46 in 2019), as well as the percentages of opposition between the examined years (41%-38%). Considering the whole Hospital DCD cornea procurement there was a similar trend (87 vs 79 donors). The DCD procurement of 'non corneal' tissues (skin, bone, eyes) even increased in 2020, and this is also due to the beginning of the new eyeball retrieval programme. Focusing then on the DBD, we observed a reduction of the numbers of brain deaths during march: the strict lockdown in Italy played a role. The organ procurement, however, increased in 2020 (34 DBD in 2020; 23 in 2019) so that the number of reported, procured, actual and used donors showed a growing trend.

Conclusions: During the pandemic, Hospice was a Covid-free department, all patients carried out three Covid-19 rhynopharingeal swab. In addition, all the preventive measures provided for visitors have been put in place. In the Hospital, the Covid-19 pandemic has not compromised the tissue/organ procurement, thanks to an early and careful planning of Hospital paths and the creation of dedicated Covid departments. There was not an increase in the rate of opposition to donation, which showed a positive attitude towards the health systems. Despite the COVID 19 pandemic, 2020 ended with an increase in organ donation and transplantation activity.

Abstract number: R-67
Abstract type: Poster

Hope during the Covid-19 Pandemic; Compassion, Humanity, Sharing Moral Distress, and Capturing Post Traumatic Growth in a Hospice Team

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Aims: Our project aims to address staff wellbeing and explore, as a hospice team, some emotional challenges presented by the COVID-19 pandemic. Difficult decision making has caused moral distress amongst staff, and it has been essential to address this in order to prevent overwhelming trauma, promote mental resilience and foster hope.

Methods: Providing a safe environment was essential for staff to share their feelings. Under the theme 'Let it go' for one week staff were asked to anonymously write down their feelings and take a treat thanking them for their input. An overwhelming response demonstrated the pressure placed on people's feelings of safety and emotional wellbeing. Hospice staff each received an anonymous personal thank you card, lifting spirits and promoting feelings of value. With staff engagement promising we posed the next question: 'What has COVID taught you?' Another positive response shown that whilst contending with morally traumatic situations in this time, staff demonstrated support for their own psychological resilience in extremely challenging situations. Feedback from this work was anonymised and displayed in the hospice, with staff were invited to view their work. Finally staff were encouraged to share their hopes and wishes for the year ahead, displaying these encouraged our team to begin looking forward and feeling hope in a difficult time.

Results: Results have been positive. A new feeling of openness and the ability to understand and reflect upon the challenges of COVID have contributed to a positive feeling in the hospice. The understanding that we all share common emotional responses is a powerful realisation, and staff have shown bravery in sharing their moral injury.

Conclusion: This project has had a huge impact. Staff have felt safe to share feelings which is essential to support resilience. It is important that moving forward through the pandemic we continue wellbeing support and nurture self-care skills.

Abstract number: R-68
Abstract type: Poster

Office-based Interventions for Acute Pain Crisis in a Palliative Care Setting during the COVID-19 Pandemic: A Case Series

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Background: Healthcare services were overwhelmed by the COVID-19 pandemic. Inpatient admissions for every pain crisis was not feasible owing to the scarcity of beds. This audit was conduced to explore the outcome of office-based interventions in managing pain crisis in a palliative care unit (PCU).

Methods: An audit of electronic records of office-based interventions performed in adult patients for pain crisis in a PCU.

Results: Thirteen office-based interventions were performed using appropriate measures in nine patients over a six month period (Table 1). The median pain score at presentation (after analgesic titration) was 8. Four patients with unilateral facial pain underwent trans-nasal sphenopalatine ganglion block (SPGB) and five patients with myofascial pain syndrome (MPS) underwent trigger point injection (TPI). All patients had satisfactory pain relief (at least 50% post procedure pain relief) and none required inpatient admission for pain management. One patient each undergoing SPGB and TPI required repeat block after 3 and 2 weeks respectively. One patient underwent SPGB thrice. Except for 2 patients, all patients had medium to long term pain relief (range 14-150 days). None of the patients experienced any adverse effect. Majority of patients had significant improvement in sleep, mood, range of motion and activities of daily living. Analgesic doses were reduced in four patients and stopped in one.

Conclusion: Office based interventions were feasible and effective in managing pain crisis and averted inpatient admission during the COVID pandemic.

Mean Age, years	53.5±12.5 years
Gender (Male:Female), n (number of patients)	7:2
Diagnosis (Cancer: Non-cancer), n (number of patients)	7:2
Ca Buccal Mucosa	2
Ca Sphenoid sinus	1
Ca Lip	1
Ca Tongue	1
Ca Pyriform Sinus	1
Ca Tongue	1
Trigeminal Neuralgia	2
Pain patho-physiology, n (number of patients)	
Mixed nociceptive-neuropathic	1
Neuropathic	3
Myofascial	5
Pain score at presentation (Mean±SD)	8.55±1.16
Site of Pain, n (number of patients)	
Face	4
Neck and Supra scapular region	5
Pain Interference, n (no. of patients)	
Sleep	9
Mood	8
Activities of daily living	8
IPM Procedure, n (number of procedures)	
Spheno-palatine ganglion block	5
Trigger point injection with local anaesthetic	8

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M-29

Hospice care provides reduction of life-sustaining treatment to advanced cancer patients in end-of-life care: An observational study.

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Background

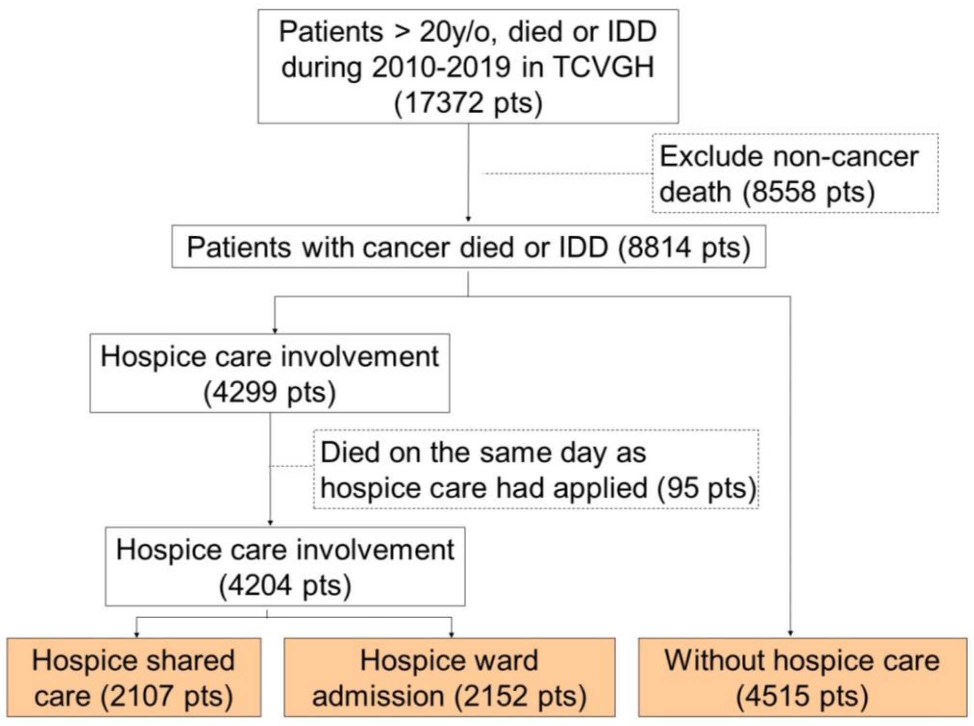
Despite the rapid advances in medical technology and drug treatment, cancer ranks first among the deaths in Taiwan since 1982, accounting for 28.6% of total deaths in 2019. Therefore, in recent decades, more and more attention has been paid to hospice care, hoping to maintain the quality of life in the terminal phase.

Besides, hospice care is associated with better end-of-life care in patients with advanced cancer [2-6]. Studies of end-of-life cancer care had been discussed both in Western countries [7-10] and in Taiwan [1], using the 6 similar quality indicators, including chemotherapy within 14 days of death, ≥1 intensive care unit admission, ≥2 emergency department visits, ≥2 hospitalizations, and receiving cardiopulmonary resuscitation, all within 30 days of death and dying in the hospital. However, there are still other important quality indicators during the terminal period, such as patients' autonomy in decision making, polypharmacy and excessive life-sustaining treatment, which had not been discussed before.

The goal of this analysis is to evaluate the effect of hospice care services on improving quality of life during the end-of-life period in the advanced and life-limiting cancer patients, especially related to patients' autonomy in decision making, polypharmacy and excessive life-sustaining treatment.

Method

This was a retrospective cross-sectional study in a single tertiary care medical center in Taiwan. Patients with advanced cancer dying in 2010-2019 were included in the study, and those who died before the age of 20 or died on the same day as hospice care had involved in end-of-life care were excluded. We divided the patients into three subgroups as follows, hospice ward admission, hospice shared care, and no hospice care involvement, reviewing their clinical characteristics, place of death, type of DNR consent, numbers of medication administration, intravenous hydration, artificial nutrition and antineoplastic drug administration, within 28 days of death.



Patients > 20y/o, died or IDD during 2010-2019 in TCVGH (17372 pts)

Exclude non-cancer death (8558 pts)

Patients with cancer died or IDD (8814 pts)

Hospice care involvement (4299 pts)

Died on the same day as hospice care had applied (95 pts)

Hospice care involvement (4204 pts)

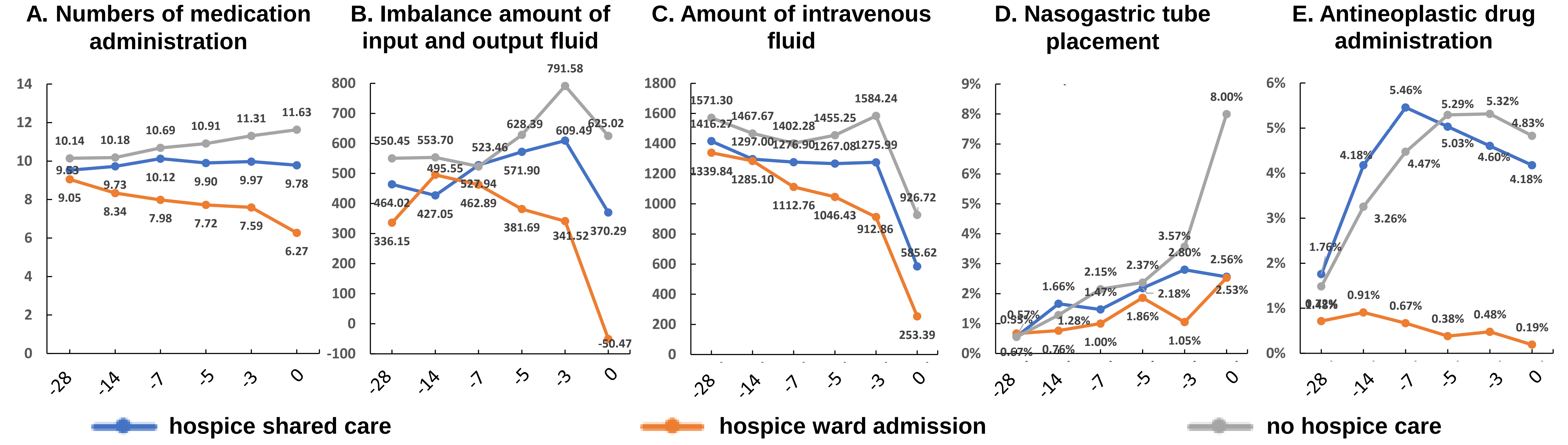
Hospice shared care (2107 pts)

Hospice ward admission (2152 pts)

Without hospice care (4515 pts)

Results

A total of 8719 patients were enrolled, and 2097(24.05%) had admitted to hospice ward, 2107(24.17%) received hospice shared care, and 4515(51.78%) had no hospice care intervention. Those admitting to hospice ward had a significant higher incidence of dying in the hospital (80.83%, vs 50.17% and 45.16%, $p<0.001$) and signing the DNR consent by themselves (48.58% vs 26.22% and 22.38%, $p<0.001$). Within the 28 days before death, those receiving hospice ward admission and hospice shared care had a significant reduction in numbers of medication administration as well as the imbalance amount of input and output fluid, the amount of intravenous fluid hydration, the nasogastric tube placement and the antineoplastic drug administration.



A. Numbers of medication administration

B. Imbalance amount of input and output fluid

C. Amount of intravenous fluid

D. Nasogastric tube placement

E. Antineoplastic drug administration

The X-axis represents the days before death. The Y-axis represents the numbers of medication in Fig. A, the imbalance amount (ml) of input and output in Fig. B, the amount (ml) of intravenous fluid in Fig. C, the percentage of NG tube insertion Fig. D and the percentage of antineoplastic drug administration in Fig. E.

Conclusions

Among adults with advanced cancer and limit life span, hospice care provided higher quality of life. Our study showed that hospice care improved patients' autonomy in decision making, reduction of polypharmacy, antineoplastic drug administration and excessive life-sustaining treatment in terminal stage of life; the influence was more significant when getting closer to the end of life.

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