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EAPC Abstracts

Welcome from the EAPC President

Dear Colleagues, dear friends,

On behalf of the Board of Directors, and as President, I am delighted to welcome you to our 12th World Research Congress of the EAPC. Again and hopefully for the last time - if the development of the pandemic allows - we are hosting this congress online. The online format has always been our second best option; however participants of the last two years were surprised about the quality of research and the level of interactivity that was possible on the virtual platform. Really appreciated by all participants was the option to watch the content of the conference on demand. For the future, we want to make sure that some of those positive aspects of the virtual congresses are also used when we can meet and exchange in person again. We have carefully analysed your feedback from the last 2 years and based on this and our growing experience we have further improved our congress platform to ensure that the EAPC congress 2022 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 350 abstracts.

There are many other people we would like to thank for their help in making this online event reality: our Scientific Committee and particularly our dedicated Chair Camilla Zimmermann, the scientific coordinators Joanne Brennan and Claudia Sütfeld and Geana Kurita, Augusto Caraceni and Luc Deliens from the European Association for Palliative Care Research Network. Our debt of thanks goes to each of them for the hard work and commitment over many long hours in 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, Catherine and Christine 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 in 2023 we will meet again in person in vibrant Rotterdam!



Professor Christoph Ostgathe
President, European Association for Palliative Care

Welcome from the Chair of the Scientific Committee

It is my great pleasure to write these words of welcome to the 12th World Research Congress of the EAPC. With the uncertainties and predicaments that our world faces today, the opportunity to gather as a community of palliative care researchers and clinicians is all the more meaningful.

Thank you to our Scientific Committee for putting together an excellent program with content for all. Our plenaries, themed sessions, and oral abstract sessions include diverse speakers from a wide range of countries and continents, presenting on important research advances ranging from tried-and-true areas of symptom management and advance care planning, to highly topical areas such as use of big data and research on wishes for hastened death.

The challenges of the last two years have brought into even sharper relief the need for equity in palliative care, and for an evidence base that supports its consistent and informed practice. Thank you for contributing to this evidence base and for your dedication to our field of palliative care.

I look forward to interacting with all of you during what I am certain will be a highly stimulating congress!

A handwritten signature in black ink, appearing to read 'C. Zimmermann', with a stylized flourish at the end.

Camilla Zimmermann
Chair, Scientific Committee
12th World Research Congress of the EAPC (Online)

Members of the Scientific Committee 2022

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Abstracts from the 12th World Research Congress of the European Association for Palliative Care

Award Lecture and Plenary Abstracts

Abstract ID: VA

Abstract type: Ventafridda Award Lecture

What Can We Learn from Conducting Controlled Clinical Trials in Palliative Care?

D. Currow

Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, Australia

Patients and their families want to know that they are getting excellent care, based on the best available evidence. Often, that evidence cannot be extrapolated from other sources given the frailty and multiple comorbidities that many people with life-limiting illnesses experience. In order to generate the best evidence, controlled clinical trials are critical for evaluating every non-pharmacological and pharmacological intervention.

The Australian national Palliative Care Clinical Studies Collaborative (PaCCSC) has randomised more than 2,300 participants to controlled clinical trials across more than twenty participating sites. This has been complemented with sub-studies that, at marginal cost, add value to the basic science of the clinical question being studied, qualitative knowledge and data for hypothesis generation.

Key learnings include:

- That there is wide variation in clinical practice in palliative care. Trying to get agreement on what is the current “standard of care” is one of the most time-consuming things in setting up palliative care clinical studies;
- Following from this directly are the arguments that occur around the use of placebo. If the standard of care varies widely and is not based on high level evidence, there is every reason to have a control arm that is a placebo;
- That we need to engage end users from the very moment of conceptualising a study – patients, caregivers, and the clinicians who will provide care especially for the patients who will never be referred to palliative care;
- That this is a team effort – every study requires an amazing array of skills and competencies in order to achieve the best possible outcome – clinicians, methodologists, ethicists and analysts;
- Patients want to participate in studies; clinicians still act as patriarchal gatekeepers far too often;
- That the design of the study is critical and elements that should be borne in mind are the primary end point being at the earliest time that you expect to see benefit (although data collection can continue long after that);
- That agreeing on a primary end point is surprisingly difficult in palliative care. For clinicians and researchers who work with symptom control, the science underpinning meaningful measurement of symptoms still requires a great deal of work; and
- Of the studies that have been done to date, a consistent finding across almost all of them is that harms that are in excess in the intervention arm and would otherwise have been attributed to disease progression are highly prevalent.

Ultimately, controlled clinical trials are feasible *and safe* in palliative care and, when practical questions are asked, will directly influence clinical care. Being prepared to measure our performance objectively is

fundamental to improving the outcomes for the people that we serve. These studies are critical not only for palliative care services but for the patients who will never be referred to a palliative care service but whose clinicians want to provide the best possible care.

Abstract ID: SA

Abstract type: Cicely Saunders Award Lecture

Promoting Quality in Palliative Care Research: Perspectives of an Editor

C. Walshe

Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom

‘You can’t make a silk purse out of a sow’s ear’.

This old Scottish proverb was one of my grandmothers’ sayings, implying that you can’t create something wonderful if the materials aren’t quite right. Perhaps this can be said from the perspective of an editor about palliative care research? I don’t mean that our research is inferior, but that the starting point for publishing work is years before writing commences. The craft of writing remains important, but there has to be underpinning high-quality research, with the potential to impact policy, theory or practice. I have had the privilege and honour to be involved in the EAPC’s research journal *Palliative Medicine* over the last decade or so, an amazing learning journey for me. *Palliative Medicine* only publishes around 20% of submitted papers, with quality being a key consideration in the decision-making process. In this presentation I will present my perspective on this as an editor.

First, the right research question has to be asked, taking account of the current state of knowledge. What is important is not just what is known and not known, but whether there is an important purpose to knowing. Second, the research design chosen to answer an important question has to be congruent with that question. Editors understand pragmatic choices, but these should be underpinned with sound appreciation of epistemological, ontological and methodological considerations. Third, the research has to be ethically and carefully conducted, with attention paid to how decisions affect the ability to answer the question(s) posed. Fourth, researchers have to understand the context in which these decisions are being made, so that they can position this research and the findings for an international audience. Then, and only then, can they consider how to approach the task of writing. Sadly, many papers don’t quite make it into the journal because it is not clear why they have asked a particular question, to what purpose, how this adds to current knowledge, and that the data are sufficient to answer the question posed.

Even with sound and important research, writing remains a key skill in enabling others to see what you have done, and why it is important. Here, there are two important considerations. First having a clear story to tell. Not a fictional story, but a focus in terms of what the data mean and how to communicate this effectively. Einstein’s mantra is sound: If you can’t explain it simply, you don’t understand it well enough. Second, enabling readers to understand what you have done (and why) so that they are assured that the conclusions reached are scientifically sound. Elegant, succinct, accurate writing is important.

The quality of palliative care research continues to improve. Our editors work alongside authors and reviewers to ensure that what we publish is the best it can be. Increasingly, this means research as a team endeavour, allowing an inter-disciplinary approach that draws from different

perspectives and expertise. This includes expanding research skills. Just as we are constantly trained and updated in our clinical skills, we should also be professionally trained in our research skills, writing and dissemination skills.

I hope, as an editor, that I am on the same side as researchers, authors, reviewers and readers, working to enable the highest possible quality of palliative care research that can make a difference to the experience of those for whom we care.

Abstract ID: PL01

Abstract type: Plenary

A Divine Intervention to Reduce Black-White Disparities in End-stage Cancer Care

H. Prigerson

Center for Research on End-of-Life Care, Weill Cornell Medicine, New York, United States

Patients with advanced cancers often seek hope, meaning and comfort from religion and spirituality, particularly as death nears. Unfortunately, while the vast majority of advanced cancer patients (88%) report that religiousness and/or spirituality are important to them, most (72%) also say that the medical system has not met these needs. Support of dying patients' religious/spiritual needs may prove especially beneficial to patients and family members who are religious, including African American (hereafter, black) patients who often rely heavily on religion to cope with cancer.

Our research has shown that advanced cancer patients who receive religious/spiritual care are not only more likely to have their spiritual care needs met, but also report less physical pain and are more likely to die where they wish compared to those not receiving such care. We find that healthcare chaplain visits promote patients' peaceful acceptance of being terminally ill, which has been linked to higher rates of advance care planning (e.g., end-of-life discussions and completion of Do Not Resuscitate (DNR) orders). Advance care planning has proved an effective way to enhance a dying patient's quality of life and the odds of getting care in line with their preferences (e.g., desired intensive or palliative care). Intriguingly, our preliminary results suggest that healthcare chaplain visits are associated with higher rates of completing DNR orders (AOR=4.50, p=0.03) among black cancer patients and higher rates of engaging in end-of-life discussions with providers (adjusted Odds Ratio=2.46, p=0.02) among white patients. *Thus, visits with healthcare chaplains appear to enhance advance care planning, but in different ways for black and white cancer patients.*

Given a long, disturbing history in the United States (US) of medical abuses committed against black patients (e.g., withholding of life-saving treatment), feelings of medical mistrust among black patients are both ubiquitous and understandable. Medical mistrust may be critical to accounting for why we find that black patients are less likely than white patients to acknowledge being terminally ill and to engage in advance care planning. Results suggest that like other religious people, black patients have a strong belief in miracles, which we show can undermine the impact of end-of-life care discussions on prognostic understanding. Because black patients often rely on religious beliefs as a basis for prognostic understanding (e.g., believing that God, not doctors, decides when one's 'time has come'), visits with healthcare chaplains may enhance prognostic understanding and black patients' sense of being seen beyond "the veil," which W.E.B. Du Bois described as obfuscating the view of another person's humanity. We hypothesize that healthcare chaplain visits may foster positive thoughts and emotions (e.g., feelings of being seen, respected, and supported, of hope, meaning, and peaceful acceptance of one's terminal illness) while reducing negative ones (e.g., feelings of being discriminated against and medical mistrust). We, thus, hypothesize that the effects of healthcare chaplain visits on advance care planning among outpatients with advanced cancer are

mediated by the positive and negative thoughts and emotions they conjure.

We also propose to evaluate the promise and feasibility of conducting a future randomised controlled trial (RCT) of early integration of healthcare chaplaincy into outpatient oncology care to promote, and reduce racial disparities in, advance care planning. Our race-specific models propose that mitigation of negative thoughts and feelings such as medical mistrust and enhancement of positive thoughts (e.g., trust, hope, and support) will mediate race-specific associations between healthcare chaplain visits in outpatient oncology settings and advance care planning.

In conclusion, we expect that the early integration of healthcare chaplaincy into outpatient oncology clinics will address unmet spiritual care needs as well as reduce black-white cancer patient disparities in end-stage cancer care and care outcomes. We welcome feedback on ways to better study the role of healthcare chaplaincy in potentially reducing black-white disparities in end-stage cancer care.

Abstract ID: PL02

Abstract type: Plenary

The Role of Big Data in Palliative Care Research

J. Cohen

End-of-Life Care Research Group, Vrije Universiteit Brussel, Belgium

The past decade has seen a spectacular evolution in data storage capacities, digitization of health information, and national policies to implement structures and procedures for data integration and access. Consequently, large datasets of routinely collected data have become available and these provide unique opportunities for health care and health care research.

In my lecture I will build on a systematic review performed by the EAPC taskforce on big data in end-of-life care research, relevant published studies, and research performed by my own team to illustrate what big data can mean for palliative care research.

Using concrete examples, I will discuss 6 functions:

- 1) **Population needs assessment and monitoring.** This is where most of the palliative care research using big data has focused on. It includes efforts to estimate the need for palliative care within the entire population, describe patterns of health care resource use or the prevalence of problems, and identify inequities in end-of-life care. The volume, velocity and veracity of big data clearly provide distinct advantages over traditional research designs such as surveys which often suffer from recruitment, retention, missing data and other issues jeopardizing the generalizability of the findings. However, content validity can be a challenge as data have usually been collected for administrative efforts other than research or evaluation
- 2) I will, therefore, illustrate how validation efforts can be undertaken to use available routinely collected data as a reliable and affordable basis for **health care system and quality of care evaluations.** Using a validated set of quality indicators data I will illustrate how the quality of end-of-life care can be compared between health care regions or health care providers and how relative performance standards can be set.
- 3) **Addressing causality.** A lot of questions around causality remain unanswered in palliative and end-of-life care. These are ideally addressed in a randomized trial. However, such trials are particularly challenging in end-of-life care populations and we cannot conduct (enough) target trials to answer all relevant causal questions relevant to palliative care. Building on insights from the so-called 'causal revolution' I will discuss the possibilities (and limits) of causal inference from observational population data.

- 4) We can then also use the data to efficiently evaluate whether **policies, interventions, programs** have their intended effects in the real world.
- 5) More **efficient data collection methods for palliative care trials**. Palliative care trials often experience serious challenges to internal validity (e.g., due to attrition and missing data) and external validity (e.g., due to pragmatic selection of participants). If the availability of big data for the patients or family carers who enroll in trials makes the studies less dependent on traditional data collection methods this may improve enrollment, retention and completeness of data. What are the opportunities and challenges?
- 6) A final function is **prediction and prospective decision support**. This is the function where the expectation (and hot stuff bias?) has perhaps been greatest. Will artificial intelligence and data-driven algorithms indeed provide palliative care with what it often promises?

Big data has several promises for palliative care research but it also suffers from several limitations and caution for overrated promises continues to be pertinent.

Abstract ID: PPL01

Abstract type: Paediatric Plenary

Children's Palliative Care Research – Goals, Challenges, Lessons Learnt and the Future

J. Downing

International Children's Palliative Care Network, United Kingdom

This paper will explore the goals, challenges, lessons learnt and the future for children's palliative care research. Whilst the number of studies and published papers in the field is growing, and the range of authors and countries involved has increased, there still remains a lack of robust evidence within the field. For example, the recently published Guidelines on the management of chronic pain in children identified '*gaps in the knowledge base and in research evidence on the treatment of chronic pain in children*'.

The goals of our research must be to reduce suffering and improve quality of life in babies, children, young people and their families with life-limiting and life-threatening conditions around the world such that they are able to 'live well until they die'. However, this doesn't mean we focus just on clinical research – whilst essential, we need to be looking at a well thought out and rounded research programme addressing a range of aspects important to the provision of children's palliative care including, but not limited to, outcomes of care, pain and symptom management, communication, spirituality, social and psychological issues, education, policy, service delivery, health systems strengthening and the cost of care provision.

Barriers and challenges to children's palliative care have been experienced and described by many researchers and practitioners. For example, Beecham et al. (2016) identified challenges such as small sample sizes, limited funding, challenges with ethics committees and societal perceptions. Alongside these, much of children's palliative care practice has been based on evidence from adult palliative care or on expert practice, medications may be being used off licence, and much of the evidence comes from high income countries. Research is often seen as 'extra', something that is done outside of our 'normal roles' and we need to look at ways of integrating research so that it is recognised as an essential component of our work. However, we need to be resourceful, to think outside of the box, and to look at ways to overcome these challenges, to learn from each other and to collaborate in order to increase the evidence base.

Despite the challenges, it is evident that it is possible to undertake high quality research with a vulnerable population such as we see in children's palliative care. There are great examples of quality studies, where

many of these issues have been overcome, where robust and important evidence has been developed. Lessons learnt from such studies will be discussed along with how we can build on these lessons, collaborate and strengthen the evidence base.

I believe that the future for children's palliative care research is exciting – multi-country, collaborative research studies are being developed and funded, multi-disciplinary studies are increasing and children and young people, along with family members are being involved in the development, implementation and dissemination of research. The range of research needed is great – studies have themselves demonstrated the range of possible research studies, along with global, regional and national priorities for research. There is also scope for collaborations with our adult colleagues as we look at studies across the life-course, health systems strengthening, universal health coverage, to name but a few. Expertise within the field, along with strong collaborations are growing. Collaborations between clinical, educational and research services, as well as with children, young people and their families, and across country. Together we can increase the evidence base and as children's palliative care practitioners world-wide we need to see the generation and utilisation of evidence as an integral part of all that we do in order to deliver evidence-based, cost-effective, equitable and effective children's palliative care around the world.

Abstract ID: PPL02

Abstract type: Paediatric Plenary

Best Practices for Involving Children and Young People in Palliative Care Research

E Namisango¹, M Friedel², L Coombes³, S Yurduşen⁴, W Alrjoob⁵, D Braybrook³, S Marshall³, G Al-arja⁵, A Roach³, S Boufkhed³, R Harding³

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Background: It is estimated that over 21 million children worldwide could benefit from palliative care each year, yet many do not receive it. The highest percentage of need is in resource limited settings, where children commonly present with advanced disease, characterized by a high symptom burden. Paediatric palliative care can alleviate these symptoms and the associated distress and hence improve outcomes of care. The WHO recommends a person-centred approach to delivering care as a way of ensuring that the care delivered mirrors the needs and priorities of patients and their families. To design robust person-centred models of paediatric palliative care, children and young people must be involved in the research which shapes the development of their services. While the art of patient involvement in research has received significant attention in adults, more needs to be done to involve children and young people in research which shapes their care.

Aim: This study aimed to identify best practices for engaging children and young people, in palliative care research, working in partnership with clinical teams and family. We draw on novel methods developed in cross-national studies, to improve the quantity and quality of primary research data collected with this neglected yet vulnerable population.

Design: Case-study approach. The five cases were part of larger programmes of work aiming to develop an outcome measure for paediatric palliative care. Four of the cases used qualitative methods (semi-structured interviews) and one used a mixed methods approach. Five research studies (case studies) from the Middle East (Turkey and Jordan),

Africa (Uganda, Kenya and South Africa), Europe (United Kingdom and Belgium). The case studies recruited a total of 244 children and young people aged 5-18 years all of whom were receiving palliative care for a life limiting/life threatening condition. We used comparative narrative synthesis to identify practices that worked well and what did not work and also identified key areas for improvement.

Results: We produced recommendations to help clinicians and researchers engage children in research:

- Age-appropriate information (with drawings) elaborated and pre-tested by children themselves, Appropriate time to decide after having the information,
- Having a distress protocol including clear sign posting to psychological support for participants if required,
- Maintaining regular communication with recruiting teams,
- Training for recruiting teams and interviewers to improve their own confidence,
- Using recruiting teams and interviewers who are well-known by children (trust) is helpful but may introduce social desirability bias.
- Time for building rapport before starting the interview,
- Refraining from using the term palliative care if it is not used by the children and young people/parents, (or at least verifying if this term has been already used or not with the children and young people /parents),
- Choice of having a parent/carer present during the interview.
- Research team being supported/advised by an advisory group of children and young people for the whole research process (especially information /consent letter, recruitment strategy)

Conclusions: This study identified best practices for engaging children and young people in paediatric palliative care research.

Themed Session Abstracts

Challenges and Opportunities in Conducting Symptom Research in Palliative Care

Abstract ID: INV01

Abstract type: Invited Speaker

Research in Non-medical Opioid Use: Overcoming the Challenges

G.P. Kurita

Rigshospitalet Copenhagen University Hospital, Department of Clinical Medicine, University of Copenhagen, Copenhagen, Denmark.

Opioids are worldwide prescribed to treat moderate to severe pain, especially in patients with cancer-related pain. In the last decades an increase on prescription of opioids for patients with non-cancer pain has been observed and alarming American reports regarding opioid misuse and related overdoses emerged. Recent data have demonstrated that non-medical opioid use (NMOU) is also frequent among patients with cancer and cancer survivors, which can severely interfere with treatment outcomes and quality of life. A few studies demonstrated a significant prevalence of patients with cancer in high risk of opioid misuse, which ranged between 19.6% and 35%. There is a clear need for more studies to analyze NMOU prevalence, predictive factors, deleterious effects, differences between different populations (countries, type of cancer, type of opioids, opioid exposure, etc.), and its development during the disease trajectory of patients in palliative care. However, several challenges impose difficulties to develop NMOU research in this area. The challenges can be related to environmental/cultural and methodological aspects. Incentives for research in NMOU may be weaker in low-income countries, where opioid availability is limited and misconceptions concerning opioid use are still very vivid. In addition, clinicians and

investigators may have the misperception that this is not an issue for palliative care patients. Regarding methodological aspects, examples are the lack of consensus regarding definitions/terms for NMOU, poor clinical documentation, lack of validated instruments for specific populations, few objective tools (mostly based on self-assessment), and losses to follow-up in longitudinal designs, among others. Suggestions to overcoming the challenges are based on knowledge dissemination through collaborative efforts to reach international consensus regarding definitions and assessment instruments, to improve research designs, and to conduct multicenter studies.

The author is in receipt of grants/research supports from Novo Nordisk Foundation, Danish Cancer Society

Abstract ID: INV02

Abstract type: Invited Speaker

Dyspnea Research: Setting a Vision

S. Mercadante

Main regional center for pain relief and supportive/palliative care, La Maddalena Cancer Center, Palermo, Italy

Dyspnea is a very distressing symptom developing in cancer and non-cancer patients with chronic diseases, particularly in the last stage, when the primary therapies fail to control the symptom. A hierarchical approach to dyspnea management is recommended, beginning with dyspnea assessment, ascertainment, and management of potentially reversible causes. A clear distinction between chronic dyspnea and episodic breathlessness which occurs in a predictable way even for minimal efforts should be performed. For planning a treatment, various variables should be taken into consideration, including the reversibility of the causes, stage, prognosis, and goals.

Nonpharmacologic interventions include airflow interventions, standard supplemental oxygen for patients with hypoxemia, and other psychoeducational and complementary approaches. However, for most patients systemic opioids should be offered. Interpretation about the benefits of opioids in literature is complex, as strict protocols do not often adhere to real conditions observed in clinical practice. Opioid doses should be titrated individually and changed according to the clinical response to optimize the balance between dyspnea intensity and adverse effects. Pre-emptive opioids should be offered for exertional dyspnea, a temporal pattern which has been identified in recent years only. Corticosteroids and benzodiazepines could be added in specific conditions. Advanced measures include high flow nasal therapy for hypoxemic patients and non-invasive ventilation for hypercapnia, if concordant with the goals and indications. Finally, dyspnea that is not responsive to these measures at the end of life is a typical indication for palliative sedation, that requires lowering the level of consciousness. These processes require high level of competence and specialized palliative care. Unmet needs of dyspnea research will be explored reporting clinical examples.

Abstract ID: INV03

Abstract type: Invited Speaker

Symptom Research in the Last Days of Life: Alleviating Suffering

M. Mori

Division of Palliative and Supportive Care, Seirei Mikatahara General Hospital, Japan

Patients in the last days of life frequently suffer various distressing symptoms (e.g., dyspnea, delirium, and respiratory secretion) that can become refractory. However, effective treatments for symptoms in this phase of life have not been fully established, partly due to the paucity of high-quality research.

Barriers to conducting high quality research in the last days of life are multifold. First, patient- and symptom-related barriers include the lack of understanding of pathophysiologic changes in the last days of life, rapidly changing symptom severity, and difficulty in obtaining consent from and enrolling actively dying patients. Second, treatment-related barriers include the lack of standardized treatment (e.g., types of medications, doses, and titration protocols) and issues regarding transfer/adaptation of knowledge. While some findings from other areas may be applied to dying patients (e.g., pain management), others may require different considerations (e.g., terminal dyspnea and terminal delirium) and more high-quality research is needed. Third, researcher-related barriers include the lack of consensus on subjective outcome measurement in patients with cognitive impairment, lack of infrastructure to conduct end-of-life research, and lack of experiences and expertise regarding research among palliative care providers. Lastly, society- and environment-related barriers include limited funding from government and pharma as well as social environment and culture with a protective position to not disturb patients in the last days of life.

In recent years, international experts have successfully completed randomized-controlled trials (RCTs) in this population and provided preliminary and/or confirmative findings that may change practice. RCTs are appropriate especially for research questions in which clinical equipoise exists and there is a certain time difference from interventions to outcome measurements. In addition to RCTs, observational studies can help describe outcomes of specific treatment and care among unselected population in the real world. Furthermore, as a patient's cognition deteriorates in the last days of life, balanced outcomes between symptom intensity and communication capacity need to be developed and utilized. Innovations are also needed to explore how to measure distress of patients with cognitive impairment. Lastly, caregivers' experiences on symptom control are important and relevant. Surveys involving bereaved family caregivers can provide useful insight into care strategies.

In this presentation, we will review recent research with different designs, summarize major challenges, and propose future research directions toward the alleviation of suffering in the last days of life.

Palliative Care Research in the 21st Century

Abstract ID: INV04

Abstract type: Invited Speaker

Can We Really Count on Big Data to Advance Palliative Care Research?

L. Morin

The increasing availability of data collected in routine clinical practice and through healthcare claims and administrative registries provides unprecedented opportunities for doing research in the fields of palliative and end-of-life care. Big data is particularly promising to overcome some of the well-known difficulties of palliative care research, such as the difficulty to recruit and retain study participants. Over the past two decades, large studies based on retrospective cohorts of decedents have proven invaluable for describing end-of-life care patterns with a high level of generalizability, for looking at places of death and transitions between care settings, for studying small patient populations or seemingly rare diseases, and for investigating the uptake of palliative care services. Wearable devices and connected sensors open up new prospects for conducting research in settings where data collection is traditionally challenging (e.g., home care) and for shedding light on functional or physiological aspects that have not yet been properly explored (e.g., using accelerometers to collect objective measures of physical mobility, or pill bottle-mounted wireless sensors to get information about symptomatic medication use). Palliative care registries, which collect detailed information about the last weeks and days of life of patients in a standardized and systematic manner, also offer considerable opportunities. However, several issues may hinder the potential of 'big data' to truly

advance palliative care research. First, size doesn't matter if the quality and reliability of data don't match their volume. Studies based on healthcare claims and administrative databases often suffer from a lack of fine-grained clinical information to characterize patients, diseases, treatments, and health outcomes. Second, although the hegemony of randomized controlled trials in the evidence pyramid is rightfully coming into question, there are important (and often misunderstood) reasons to be wary of observational data to evaluate the comparative effectiveness and safety of medical interventions in the context of palliative and end-of-life care. Replacing the magic of randomization by the myth of real-world evidence would be a serious mistake and lead to dangerous conclusions regarding "what works" for patients with advanced illness. Third, we must strive to incorporate patient-reported outcomes measures (PROMs) and caregiver-reported outcomes measures (CROMs) into routinely collected data systems: palliative care research can hardly move forward without high-quality data about symptoms, quality of life, or self-reported priorities regarding treatments and care. Fourth, it has been shown repeatedly that mortality follow-back studies (namely, retrospective cohorts of decedents) can—under certain conditions—paint a biased and unrealistic portrait of end-of-life care. Yet, little efforts have been put into trying to improve the identification of 'dying' patients and patients in need of either generalist or specialist palliative care in prospective cohorts. Finally, very large datasets with millions of patients and trillions of measures will be of little value if they do not come with contextual information about the underlying reality that these data capture. For example, studies looking at the potential effect of receiving specialist palliative care on subsequent health outcomes are difficult to interpret without specific facts about how palliative care services are organized and what specialist palliative care entails in the context of the healthcare system in which studies are conducted. Given the anticipated growth in the volume of data available to health researchers within the next 5–10 years, we believe that several key conditions should be met for 'big data' to truly advance palliative care research. Among them, there is a need for a better integration of advanced epidemiological methods within palliative care research teams and for stronger cooperation between these teams and experts from other fields of research (e.g., computer sciences, artificial intelligence, linguistics, pharmacoepidemiology, predictive modelling). Public and patient involvement should also become part of every new research project to make sure that the inherently limited resources we have at our disposal to shed light on palliative and end-of-life care are dedicated to issues that patients, relatives, and clinicians find important: 'big data' will only make a difference if we can leverage high-quality information to ask questions that matter and to provide answers that are useful.

Abstract ID: INV05

Abstract type: Invited Speaker

Machine Learning in Palliative Care

C. Lindvall

Computational Palliative Care Research Lab, Dana-Farber Cancer Institute, United States

Patients living with cancer have a multitude of distressing and often severe symptoms related both to their cancer and to the side effects of treatment. Symptom burden and treatment-related adverse events are critical outcomes for observational cancer research and population-level surveillance. However, extracting structured data on symptoms at scale is a major challenge. Machine learning techniques are increasingly important tools in extracting oncologic endpoints from unstructured electronic health records data. In this presentation, I present a framework for applying machine learning to unstructured clinical notes to extract data on patient symptoms. I will show how these data are integrated into the clinical workflow at a large cancer center to identify patients with palliative care needs.

Abstract ID: INV06

Abstract type: Invited Speaker

Is There a Role for New Technologies in Palliative Care?

T. Steigleder

University Hospital Erlangen, Germany

The development of palliative care took place while high-tech intensive care was beginning its triumphant march. To some extent, palliative care was also a response by the medical community to this new way of caring for patients that focused less on the person, their history and dignity, and whose services were based on overwhelming technical progress.

With palliative care, personal encounter and sharing the burden of advanced diseases are the centre of health care. This is one of the great strengths of palliative care and directly benefits our patients and their families.

Can new technologies support our work in any significant way?

While we engage in our work as individuals, we use our subjectivity and empathy to best care for our patients and their families. However, objectivity and comprehensive data can also help us to do this. We already utilise this by using all the diagnostic tools at our disposal to approach questions that are crucial for our patients, their families and our treatment planning: what is the expected further course? What symptoms may occur? Which symptoms may not be expressed verbally or explicitly due to changes in alertness? What is the expected remaining time of life? However, in palliative care in particular, a very cautious approach is taken to answering these questions. One of the provisos is to weigh diagnostic procedures carefully against the expected benefit for the patient. In this context, examination procedures should not be burdensome or should be as little burdensome as possible. They must also not interfere with social participation. Another aspect is the legitimacy of the application of the diagnostic procedures: is it in the interest of the person concerned to ask the question and answer it in the best possible way. On the other hand, should this question not be asked at this point, like the question about the expected remaining life span, for example?

And here lies the strength and advantage of new technologies in palliative care because we can bring these thoughts into the research and development of said new technologies. How can technologies be created that generate reliably objective and quantifiable data, but do not disrupt social participation and preserve the natural handling of the last phase of life? What ethical, social and legal implications must be considered and explored in the research and development of these new technologies?

In this way, with the research and development of new technologies, palliative care can bring the values and attitude that are intrinsic to itself into future diagnostic procedures.

The advantage that palliative care can create here for patient care in general is non-invasive and patient-friendly procedures for diagnostics and monitoring in all areas of medicine, as well as a new and heightened awareness of ethical, social and legal implications of medical technology from digitalisation to innovative sensor technology.

For its own field, palliative care can add more comprehensive, objective and quantifiable data to the valuable work of staff. For example, with the help of digital systems and artificial intelligence, the diversified knowledge of a multi-professional team can be made available to team members in a user-specific and needs-based manner. Innovative, contactless and stress-free sensor technology can provide around-the-clock data on vital parameters such as heart rate or heart rate variability, which may offer us indications of symptom burden or critical health changes, for example.

New technologies in palliative care can provide significant support to the wonderful people who do so much there, offering more treatment certainty, helping to use resources more efficiently and supporting decision-making. Moreover, the research and development of new technologies has the great advantage of bringing the values and attitudes of palliative care into the new technologies from their inception.

Palliative Care Research in the Era of COVID-19

Abstract ID: INV07

Abstract type: Invited Speaker

Palliative Care in the UK During the COVID-19 Pandemic: Provision, Policy and Practice

K. Sleeman

Laing Galazka Chair in Palliative Care, Cicely Saunders Institute, King's College London, London, United Kingdom

The UK has a global reputation for provision of high-quality palliative care. Yet hundreds of thousands of people die each year in the UK needing palliative care but not receiving it. And there are persistent - and increasing - inequalities in access to palliative care including by age, diagnosis, deprivation and ethnicity. Projections studies have shown large increases in the future palliative care needs which will be driven by ageing and dementia, populations that can be least likely to access palliative care.

The COVID-19 pandemic provided a stress-test for palliative care. Over 150,000 people have died from COVID-19 in the UK to date. The place of death in the UK has shifted into the community, with a 41% increase in home deaths during 2020. Care home deaths increased three-fold during the first pandemic wave. However, data from primary care and care homes indicates poor integration of palliative and end of life care across care settings; and the experiences, care needs and outcomes of people dying in community settings during the pandemic have had little scrutiny.

This presentation will draw on data from three research studies: the CovPall and CovPall_CareHomes studies, and the Marie Curie Better End of Life programme. Data from these three studies will be used to consider (i) what we learnt about provision of palliative and end of life care during the COVID-19 pandemic, and (ii) how this data has informed priorities for strengthening palliative care beyond the pandemic.

The author has received research grants from the National Institute of Health Research and Marie Curie. The post of Laing Galazka chair is funded by an endowment from Cicely Saunders International and Kirby Laing

Abstract ID: INV08

Abstract type: Invited Speaker

Smartphone Based Telemedicine Service as an Acceptable Model of Care for Cancer Patients in Resource Limited Settings During COVID-19 Pandemic: An Observational Study

S. Bhatnagar

Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi, India.

Background: The COVID-19 pandemic hampered the palliative care services due to the policies of nationwide lockdown, social distancing and patient triaging. Telemedicine can be a possible solution to overcome the hurdles of providing holistic care to cancer patients by minimising the visit of patients to the healthcare facility.

Aim: The objective of the study was to evaluate and assess the feasibility of telemedicine as a tool to provide palliative care during the COVID-19 pandemic in resource limited setting.

Design/Participants: A retrospective study was conducted to analyse the telemedicine service from 25 March 2020 to 30 June 2020. Patients who availed the teleconsultation services during this period were recruited. A smartphone-based 24/7 model for conducting audio-visual consultations was created whereby patients could interact with a trained palliative medicine physician. The study explored the reason for teleconsultation, main barriers for hospital visit, and patient satisfaction.

Results: Out of the 547 patients, 462 (84.46%) utilised voice calling service. The major reason for not visiting the hospital was issues with

transportation (48.8%) followed by fear of contracting COVID-19 (37.3%). The majority of the calls (63.62%) were regarding uncontrolled symptoms related to primary disease. 402 (73.49%) patients were very satisfied, and 399 (72.94%) decided to use telemedicine in future as well.

Conclusion: Telemedicine is a helpful tool to provide integrated palliative care to cancer patients who are unable to visit hospitals regularly. This was observed to be especially useful during the pandemic in a resource limited setting.

Abstract ID: INV09

Abstract type: Invited Speaker

Research on Advance Care Planning in Nursing Homes During the COVID-19 Pandemic

N. Preston

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Introduction: Staff and the public have limited access to information about advance care planning. Yet, during the pandemic there was an urgency to complete advance care plans (ACP) in long term care facilities (LTCFs) or 'Emergency care plans' which focussed upon future care choices relating to hospital admission and resuscitation status.

Materials and Methods: Three studies addressed ACP in care homes: Evaluating experiences of LTCFs during the pandemic including their experiences of ACP. Semi-structured interviews with staff (16), community staff (11), residents (3) and families (5) from 11 LTCFs analysed using thematic analysis.

International implementation case study of ACP training for staff caring for residents with advanced dementia, which was adapted from in person to asynchronous online training during the pandemic. Evaluation interviews in the UK were conducted with staff (78) and families (34).

Bespoke online training and informational resources about advance care planning during COVID-19 was developed for staff and families. Semi-structured interviews conducted with families (37) and staff (35) from eight LTCFs.

Findings: Staff were concerned about the initiation of ACPs from external agencies and why they were implemented. Staff felt abandoned thinking ACPs meant they were going to be left to manage on their own, adding to their emotional distress.

Differences were found between the two training mechanisms, which will be discussed but related to mode of delivery. In study 3, the bespoke training, (<https://covidacpcarehomes.com/care-staff/units-training/>), was found to be accessible and easier to engage with compared to information from other agencies. Staff felt it gave them permission to engage in these conversations, recognise when a resident gave them cues to have an ACP discussion, when they needed input from senior staff. Staff revised their ACP procedures.

Similarly, families felt emboldened to challenge decisions. They shared training with other family members, increasing dissemination. A section on supporting yourself was particularly well evaluated as this met the emotional burden staff and family had identified in study 1.

Different implementation challenges were identified in study 2 and 3. Working remotely meant homes need to have appropriate and functioning technology. Building relationships with families was critical and challenging when engaging remotely. Recruiting and establishing meaningful relationships with staff and family carers was critical and challenging in the context of buy-in and willingness to participate.

Study 3 involved skilling up staff whereas study 3 involved both skilling up and arranging a family conference, which was less successful perhaps due to the constraints of the pandemic.

Conclusion: Whilst advance planning had initially raised concerns for staff, the training helped staff and families' understanding of advance care planning. Bespoke training was particularly well received but involving families remotely was challenging. It is possible for staff to be

upskilled and do ACP during a pandemic, but it is difficult, and we need to be aware of the many contextual factors – including how studies can be designed to be workable in difficult circumstances. More research is needed on facilitators and barriers to ACP in LTCF both during a pandemic and more generally.

How to Perform Research Regarding Wishes for Hastened Death

Abstract ID: INV10

Abstract type: Invited Speaker

Wishes for Hastened Death: How to Bring Evidence into National Guidelines

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Background: Desire to die, understood as a broad phenomenon, is common in patients receiving palliative care. A desire to die may have diverse forms, backgrounds, meanings, and functions. Possible forms of desire to die include the acceptance of death or satiety of life without any pressure to act, but also the wish to hasten death or latent to acute suicidality (with deliberate action plans). The latter may also imply a wish for medical aid in dying, i.e., euthanasia or assisted suicide. Euthanasia ("termination of life on request", §216 German Criminal Code) is currently forbidden in Germany, the legal restrictions with regard to assisted suicide ("assistance of suicide with intent of repeated conduct", §217 German Criminal Code) has been repealed by the *National Federal Constitutional Court* in February 2020. Possible new regulations are currently under discussion. This dynamically changing legal situation adds to health professionals reporting uncertainty in dealing appropriately with a desire to die.

Methods: As part of the new extended version of the *German Palliative Care Guideline for Patients with Incurable Cancer*, an interdisciplinary and multi-professional working group developed evidence and consensus-based statements and recommendations on desire to die. The best available evidence was identified through systematic literature searches and by asking experts for further known quantitative as well as qualitative literature. Included publications were assessed as recommended by the *Scottish Intercollegiate Guidelines Network* (SIGN). Due to the limited availability of high-quality empirical publications related to desire to die, close attention was paid to national clinical expertise to develop recommendations. Consensus for these recommendations was reached at a conference of the guideline group consisting of elected representatives from 61 professional societies and patient associations. At least 75% of those present approved each recommendation.

Results: The expert panel developed and agreed on 21 statements and recommendations on desire to die and related phenomena. A descriptive definition was agreed upon of desire to die as a complex phenomenon with individual causes, manifestations, and consequences. The potential background of desire to die, its meanings, functions and possible interventions are described. The guideline recommends proactively addressing and exploring a potential desire to die as the intervention that should be considered before all others. This recommendation is based on evidence from studies on suicidality, in which no negative effect of asking study participants about suicidality were found.

Conclusions: The guideline informs health professionals, how to care for and communicate with patients who are receiving palliative care and who express a desire to die. Meanwhile also data is available, that open conversations about desire to die through trained health professionals do not harm palliative patients but might lead to an at least temporary relief of suffering. Therefore, health professionals can feel encouraged to promote an open and respectful atmosphere of conversation about

existential issues at the end of life including possible desire to die. To support health professionals in this, trainings on the topic are conducted. The author is in receipt of grants/research supports from Association of the Scientific medical Societies in Germany, German Cancer Society, German Cancer Aid

Abstract ID: INV11

Abstract type: Invited Speaker

Researching Medical Assistance in Dying: Lessons to Learn from Canada

B. Pesut

School of Nursing, The University of British Columbia, Canada

Medical Assistance in Dying (MAID) was legalized in Canada in 2016. Persons can choose either clinician-administered or self-administered MAID; although, the vast majority in Canada are clinician-administered. Canada is unique in that nurse practitioners, who are registered nurses with additional education at the post-graduate level, can assess for MAID eligibility and provide MAID as part of their independent scope of practice. Recently, Canada revised the original 2016 legislation to permit MAID for those whose natural death is not reasonably foreseeable. This has resulted in two sets of safeguards; the key difference being a 90-day reflection period for those whose natural death is not reasonably foreseeable.

The most recent report (2020) on MAID in Canada indicates that MAID currently accounts for 2.5% of all deaths in Canada; although, this percentage varies significantly across the 10 provinces and 3 territories. The numbers of persons choosing MAID grew by 34.2% between 2019 and 2020.

Our program of research in MAID began in 2017. We are currently conducting a longitudinal qualitative and policy study on strategies to relieve suffering at end of life including MAID and palliative care. We have learned five important lessons for conducting research in the area of MAID.

First, create a diverse team and embrace some tension. Often, we think about disciplinary diversity when constructing our teams. But, in the context of MAID, it is also important to think about moral and ethical diversity. If your team goal is to provide a rich and nuanced description of what can be a morally contentious practice, then it is important to build in diverse perspectives. Such diversity can help to challenge research team members' deeply held assumptions and assist with looking at data in new ways.

Second, use research methods that will uncover the details. Even though MAID is legislated at the Federal level in Canada, the provinces and territories have some leeway in how they implement MAID services. This includes the way MAID is organized and the enactment of additional regulation at the provincial and territorial level. These decisions have an impact on the quality of care available to patients. Qualitative methods are particularly useful in understanding how local policies and practices are affecting care quality and in assisting with the interpretation of population level quantitative trends.

Third, take a docu-series not a snapshot. Since legislation in 2016, the evolution of MAID in Canada has been a rapid one. Legislation has already been amended significantly, and local policy changes soon follow. The comfort level of healthcare providers with MAID practice evolves over time as team and relational dynamics find a steady state. This means that knowledge quickly becomes outdated and longitudinal research is particularly important.

Fourth, be a political strategist. MAID research has political implications. As such, it is important to use language carefully, anticipate and manage the impact of research outcomes, and try to balance equity and empiricism. Striving for some degree of objectivity, alongside an ethical commitment to equity, will facilitate your access to a broader group of stakeholders.

Fifth, embrace your inner philosopher. Theory from the social sciences can provide unique insights into MAID empirical work. Indeed, it may be

difficult to make sense of some research findings without these insights. In Canada, MAID developed as a healthcare act, but from a research perspective the theoretical developments must transcend the biomedical lens typical of healthcare research.

Special thanks to team members Sally Thorne, David Wright, Catharine Schiller, Margaret Hall, Janet Storch, Michael Burgess, Mike Banwell, Kenneth Chambaere, and Carol Tishelman

The author receives research funding from the Canadian Institutes of Health Research

Abstract ID: INV12

Abstract type: Invited Speaker

The Impact of Assisted Dying Legislation on Palliative Care Practice

S.M. Gerson

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Background: Assisted dying laws in several areas of the world present different challenges and opportunities for palliative care practitioners and researchers. This presentation will draw from qualitative research conducted about the impact of assisted dying on palliative care practice.

Aims: To summarise research experiences about the impact of assisted dying on palliative care practice in areas where assisted dying is legal.

Methods: Two qualitative interview studies about assisted dying and palliative care were completed by the presenter: one in the US state of Washington investigated hospice professionals' experiences with assisted dying (n = 21), and another investigated the relationship of assisted dying with palliative care in three jurisdictions: Oregon, US, Quebec, Canada and Flanders, Belgium (n = 29). The latter study was funded by Wellcome Trust and conducted in coordination with members of the End of Life Studies Group at the University of Glasgow.

Results: Results identified that the impact of assisted dying on palliative care depends on many factors, including details of each law, the cultural or institutional setting, palliative care approach, the practitioner, and the individuals involved. In some areas practitioners are challenged by changing legislation and institutional policies that are contradictory, and researchers must navigate shifting conditions, their own experiences, biases, and assumptions.

Conclusion: There is no one uniform relationship between assisted dying and palliative care. As legislation for assisted dying is passed around the world, palliative care practitioners and researchers need to evaluate opportunities while navigating challenges as they investigate how to improve care and address desire for hastened death.

EAPC Researcher Awards

Abstract ID: INV13

Abstract type: EAPC Early Researcher Award

Palliative Care and Poverty Reduction: Building a Business Case for Palliative Care Within Universal Health Coverage in Low and Middle-Income Countries

J. Bates

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Although palliative care is included within the definition of Universal Health Coverage and supported as a value-for-money intervention by the World Bank, it is estimated that only 12% of adults and children with serious health-related suffering receive the care they need. Over 80% of this need is in low- and middle-income countries (LMIC). Economic arguments have supported improved access to palliative care in some high-income countries. Early data and advocacy proposals

suggest that palliative care can support household poverty reduction in LMIC.

This presentation reports mixed methods research conducted in Malawi, a low-income country in South Central Africa, with households affected by advanced cancer. Using a capabilities approach, poverty reduction was understood beyond financial protection from costs of non-beneficial healthcare, to include enhanced wellbeing at household level. Patients and family caregivers used Photovoice to describe concepts of wellbeing and the role of palliative care. Data elicited using this novel community-based visual participatory method informed the development of the Patient and Carer Cancer Cost (PaCCCT) Survey for use in populations receiving palliative care in LMIC. This survey was administered in a prospective observational cohort study of 150 households (150 patients and 121 caregivers) at the time of diagnosis of advanced cancer and then at one, three and six months following diagnosis. Direct and indirect costs and disavowing were reported. Multiple linear regression models for total household costs of healthcare and risk ratios for catastrophic costs, calculated as $>$ or $=$ to 20% total household income, were tested by receipt of palliative care.

Patients and family caregivers engaged actively and safely as co-researchers in Photovoice, although participation was limited for those who were older and/or more physically impaired. Wellbeing was understood as being happy, having courage and seeing improvements in the patients' condition. The ability to work and/or be part of the community was valued to avoid discrimination which was described as being 'prematurely dead.' Palliative care supported capabilities through the provision of medicine, hands-on care and counselling. The cohort study reported outcomes at six months. Patients in 89 (59%) households were alive, 55 (37%) had died, and 6 (4%) households were lost to follow up. The average age of patients was 50 years (IQR 40-57). Overall, 21% of households received palliative care (7% of rural households). 64% of households experienced catastrophic costs, 47% (9/19) of households who received palliative care vs 69% households (48/70) who did not (RR: 0.69, 95% CI 0.42, 1.13). Palliative care was associated with reduced disavowing (\$11 vs \$34, $p=0.005$). The mean difference in total household costs of healthcare was not significant (-36% with receipt of palliative care $p=0.707$).

Palliative care was found to have the potential to support household poverty reduction in Malawi, supporting Sustainable Development Goals 1 and 3. Access to palliative care was poor, particularly for those in rural areas. Larger multi-centre studies are needed to confirm the reductions in catastrophic costs and disavowing described and for diagnoses beyond cancer. Novel and/or integrated models of care are needed to improve access to palliative care, particularly in rural areas.

The approaches, methods, and results reported present new economic evidence to progress research and support advocacy efforts to improve access to palliative care in LMIC. These are critical to inform policymakers and funding bodies that palliative care provides support beyond the individual at the end-of-life, delivering poverty reduction to households well before and beyond the time of death. Future research should continue to engage global health and development goals to ensure that no one is left behind in the pursuit of inclusive Universal Health Coverage.

Abstract ID: INV14

Abstract type: EAPC Early Researcher Award

End-of-Life Communication in Nursing Home

S. Gonella

Azienda Ospedaliero Universitaria Città della Salute e della Scienza di Torino, Torino, Italy

This research was inspired by Gastmans's dignity-enhancing care framework which is based on three aspects: lived experience, interpretative dialogue, and normative standard. Against this background, Gastmans identified three key concepts in providing care including vulnerability, care, and dignity, and defined good care as the care that through a shared dialogical process of communication deals with a person's vulnerabilities and supports dignity. Thus, the decision to explore how communication

may support dignity of extraordinarily vulnerable people as those who live in nursing homes (NH). The decision was sustained by 1) the increasing number of elders with chronic progressive illnesses and evolving patterns of comorbidities who spend part of their remaining life in a NH. These people may benefit from care aimed at maximizing the quality of their remaining life rather than from life-sustaining treatments; and 2) evidence that clear and timely end-of-life communication about goals of care and treatment decisions between healthcare professionals and residents and their family carers promotes high-quality care at the end of life.

Firstly, a conceptual model of good end-of-life care according to the perspective of family carers of NH residents dead or approaching death has been developed, by performing a systematic review of qualitative findings. This review suggests that trigger events impact on family carers' acknowledgement of the 'not return point' of the situation and offer the opportunity to discuss their relative's conditions and the need to adjust the care plan. If a trigger event occurs and it is recognized, the question is called and care may start to shift towards a palliative-oriented approach. A patient-centred environment may partly influence this process. Simultaneously, the association between healthcare professionals-family carers end-of-life communication and end-of-life care outcome was evaluated and the meta-analysis shows that communication was positively associated with the family's decision to limit or withdraw life-sustaining treatments (odds ratio=2.23, 95% confidence interval: 1.58-3.14). Secondly, the potential mechanisms by which end-of-life communication may contribute to palliative-oriented care at the end of life were hypothesized and then tested by interviewing 32 bereaved family carers and 14 nurses across 13 Northwest Italian NHs. End-of-life communication appeared to act through four main mechanisms: (i) promotion of family understanding about their relative's health conditions, prognosis, and treatments available; (ii) fostering of shared decision making between healthcare professionals and resident/family carers; (iii) using and improving knowledge of resident's preferences for end-of-life care; and (iv) family carers' preferences for their relative's end-of-life care. Thirdly, the model was expanded by positing and verifying that the NH environment could influence the transition towards palliative-oriented care at the end of life by affecting the onset and quality of communication. Finally, a first theory attempting to describe the contribution of end-of-life communication to palliative-oriented care in NH was developed by employing a descriptive two-tailed embedded multiple-case study based on 23 paired interviews between bereaved family carers of NH residents and nurses. Paired interviews showed family preferences to be the strongest mechanism in arranging the end-of-life care plan with a direct impact on the final care provided. Instead, although it was clear that family understanding and shared decision-making have a positive impact on end-of-life care, they did not appear to be essential to provision of palliative-oriented care at the end of life. Finally, residents' preferences were often poorly known, with a limited impact on the end-of-life care goal.

This theory is currently being refined based on data collected during a transnational multidisciplinary implementation study, known as mySupport study, that involved a consortium of six countries (Canada, United Kingdom, Ireland, Italy, Netherlands, and Czech Republic) and explored the benefits of structured family care conferences associated with written information in supporting family carers of NH residents with advanced dementia who have to take decisions for their relative's end-of-life care.

Abstract ID: INV15

Abstract type: EAPC Post-Doctoral Award

A Child is Not a Small Adult: Challenges and Opportunities of Integrating Knowledge of Adult Palliative Care Research in Pediatric Palliative Care Research

K. Beernaert

In this presentation, I will first shortly introduce my personal trajectory in palliative care research and present the organization of (paediatric) palliative care in my country. This will be followed by showing some of

my major contributions and faced challenges and opportunities in the field of paediatric palliative care as it was the EAPC paediatric task force who nominated me for the EAPC post-doctoral award.

I have started in palliative care research in 2011 by focusing on the early palliative care needs of adult people with cancer, COPD, heart failure and dementia. At this point, I am a senior researcher responsible for two programs in our End-of-Life Care Research Group at the Vrije Universiteit Brussel and Ghent University in Belgium. These research programs are 1) palliative care for people with cancer and 2) pediatric palliative care. Whereas the numbers of children living with and dying from serious illness are notably smaller than those of adults, they are still considerable. Therefore, I investigate ways to reduce suffering and improve the well-being of seriously ill children and their families.

Especially for this presentation, I will focus on how we can use the increased knowledge and expertise from adult palliative care for the growing field of pediatric palliative care. I will go deeper into the pitfalls we need to overcome, and how to do this creatively but wise. We need to consider that children are not small adults: broad developmental spectrum, rare conditions, smaller numbers, the protection of children/parents, children's experiences with being ill, the family context, the "worth" of child's life etc. I will apply this to some concrete recent examples I have worked on: newly developed quality indicators for end-of-life care in children with cancer, neurological or congenital conditions, tools to improve patient- and family empowerment in advance care planning and palliative care, and the development of a perinatal palliative care intervention.

Abstract ID: INV16

Abstract type: EAPC Post-Doctoral Award

When the "Dismal Science" Meets Incurable Illness: Researching the Economics of Palliative Care

P. May

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I started working in the field in 2010, when Trinity College advertised for a junior researcher to conduct literature reviews, and economics and policy analysis. I had the methods skills but knew nothing about the subject; my interview preparation began by reading the Wikipedia article on this thing called "palliative care". Once in post, I was immediately struck by a couple of distinctive aspects. First, it had been known for a long time that the last year of life was the highest cost, and that this expenditure yielded poor value with extensive prevalence of modifiable problems. Second, generic evaluation methods did not seem very well suited to the context. These appeared very serious issues, yet there was a dearth of research activity on what we might do about them. Palliative and end-of-life care was considered an obscurity within health economics, when dying and death are by definition universal concerns. For a pre-doctoral researcher in search of a focus, this was a heady mix: the promise of doing something new and intellectually adventurous, *and* of making a difference by addressing unusually large, increasingly urgent evidence gaps.

Twelve years later and I am always grateful for ending up, quite by chance, in this field of research. I have benefited from involvement with a wide range of colleagues from around the world, across many disciplines and backgrounds, and at all career stages. This highly collaborative global network was something I could never have anticipated when I started out. Of course, knowing this landscape, the list of names that precede me in the EAPC Researcher Awards, and the quality of work now undertaken by my peers, makes my nomination for this award all the more appreciated.

In my presentation I will recap my research with many of those collaborators. I will discuss how we identified the timing of palliative care involvement as central to its economic effects, how treatment effects vary by comorbidity burden, and how economists think about these

results. While it's nice to reflect on past achievements, I am not really interested unless they inform our current and future efforts. I am much more preoccupied with the countless things we didn't get to yet. As such I will briefly summarise my current priorities, and I will argue that building this evidence base is a two-way street. Economists may have paid insufficient attention to incurable illness, but palliative care research could also do more to incorporate the economic perspective. Economics has been called the "dismal science", and in end-of-life care may be misunderstood as putting a price on things that cannot be valued. To me, economics is nothing more than a tool to manage the fact that we will always face more health-related problems than we have resources to address those problems. In this sense economics and palliative care are natural partners: both exist to improve decision-making between difficult, sometimes dismal choices. And by working together more closely we will improve the prospects for people with serious illness and their families to get the care and support they deserve.

High Scoring Abstracts

Abstract ID: HS01

Abstract type: High Scoring

Cochrane Pain, Palliative and Supportive Care (PaPaS) Group Review of Spiritual and Religious Interventions for Adults with Terminal Illnesses, 2011-21. Update of Candy et al. 2012

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Background/aims: People with terminal conditions towards the end of life may ask "Why me?" or raise other questions or concerns with existential, spiritual and/or religious aspects. Studies have shown that addressing spiritual and/or religious needs may benefit physical and emotional as well as spiritual wellbeing.

Aim: to update a 2012 Cochrane review of randomised controlled trials (RCTs) of spiritual and religious interventions for adults with terminal illness and evaluate their effectiveness.

Methods: We systematically searched six databases: AMED, CENTRAL, CINAHL, EMBASE, MEDLINE, and PsycINFO from Nov 2011 to Jan 2021, for RCTs of spiritual or religious interventions, alone, or with such a component, conducted with adults with terminal illness. Primary outcomes were spiritual or psychological wellbeing, quality of life, coping, and death distress or quality of death/dying.

Two review authors independently screened citations, agreed full-text papers for retrieval, assessed texts for inclusion, discussed differences, and agreed the final set. Data extraction is in progress; when complete we will evaluate study findings and designs, including randomisation and risk of bias.

Results: We identified 2282 citations, retrieved 79 full-text papers, and included 23 of these, a far greater proportion than the original review (23/2282 vs 5/3868).

The 2012 review concluded that its five RCTs, all in USA, lacked quality and clarity, with evidence for efficacy inconclusive.

Our included studies had more varied designs and were more geographically diverse, including China, Europe, Iran, Hong Kong, Kenya, Malaysia, and Thailand, as well as USA. Participants' conditions included heart failure, HIV+, and Parkinson's.

Our review will be finalised in Dec 2021, with full details of all studies' characteristics and effectiveness.

Conclusions: More RCTs are being conducted in this field, with greater geographic and methodological diversity. Study quality is still variable, but overall has improved in the last ten years.

Abstract ID: HS02

Abstract type: High Scoring

The Feasibility, Efficacy, and Safety of the Modified Comprehensive Treatment Algorithm for Terminal Cancer Dyspnea: A Multicenter, Prospective, Observational Study

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Background/aims: How physicians treat terminal dyspnea varies markedly, which could hamper quality care. While a prior study proposed a preliminary treatment algorithm (Mori M, et al. JPSM 2021), it involved only opioids and proxy measurements, and only 24-hour outcomes were reported. We have modified the algorithm, and included comprehensive treatment options (e.g., opioid titration/switching and benzodiazepines) as well as patient-perceived goal achievement and dyspnea intensity. We aimed to examine the adherence to the modified algorithm-based treatment for terminal dyspnea, and explore its efficacy and safety over 48 hours.

Methods: In this multicenter prospective observational study, we consecutively enrolled advanced cancer patients who had ECOG PS=3-4, moderate to severe dyspnea, and maintained communication capacity. Participating palliative care physicians initiated parenteral opioids, choosing whether to use the algorithm based on their preference. The primary endpoint was the adherence rate to the algorithm over 24 hours (a priori goal=70%). We also examined the adherence, goal achievement, dyspnea intensity (numerical rating scale: NRS), and adverse events daily over 48 hours.

Results: All 108 patients who were enrolled received the algorithm-based treatment (mean age, 72). Of 96 and 87 patients who remained alive at 24 and 48 hours, respectively, 96 (100%) and 82 (94%) adhered to the algorithm, respectively, and 66 (69%) and 64 (74%) achieved goals in dyspnea relief, respectively. In a complete case analysis using paired t-tests, mean dyspnea NRS scores significantly decreased from 7.3 (standard error=0.2) at baseline to 4.9 (0.3) at 24 hours (n=72; p<0.001), and 7.2 (0.3) at baseline to 4.6 (0.4) at 48 hours (n=55; p<0.001). Adverse events were rare.

Conclusions: We confirmed the feasibility, efficacy, and safety of the modified algorithm-based treatment. Its implementation may better help physicians provide quality care for terminal dyspnea.

Abstract ID: HS03

Abstract type: High Scoring

The Impact of Transmural Palliative Care Initiatives on Healthcare Costs in The Netherlands: A Registration-Based Study

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Background/aims: Coordination and continuity of palliative care across different care settings is important to meet the values, wishes and needs

of patients and relatives. In the Netherlands, transmural palliative care is rising. Insight into its challenges, including organisation and funding, added value and costs can contribute to further implementation. The aim of this study was to describe and assess the effect of transmural palliative care on healthcare costs in the last 30 days of life of deceased adults in the Netherlands.

Methods: Using administrative insurance data of all adults who died in the Netherlands between 2016 and 2019, we compared healthcare costs in the last 30 days of life between adults who received transmural palliative care in six frontrunning regions or not. We compared adults receiving transmural care with a 1:1 matched control group, matched by age, sex, cancer diagnosis (yes/no), year of death, and region. Descriptive statistics were used.

Results: Median healthcare costs in the last 30 days of life in both groups were 6.906 euros per patient (IQR 7.627). Median costs per patient for 210 adults receiving transmural palliative care were 6.449 euros (IQR 7.172) and for the matched control group 7.031 euros (IQR 8.257). Median hospital care costs per patient for adults receiving transmural palliative care were 1.053 euros, median costs for the general practitioner, 752 euros and for home nursing 1.844 euros. For the matched control group, median hospital care costs per patient were 2.623 euros, median costs for the general practitioner were 317 euros and for home nursing 153 euros.

Conclusions: Healthcare costs in the last month of life are lower for adults who received transmural palliative care compared to adults not receiving transmural palliative care. These healthcare costs seem to be shifting from hospital towards primary care.

Oral Abstracts

Methodology

Abstract ID: OA01:01

Abstract type: Oral Abstract

A New Framework of Core Research Competencies for Palliative Care Clinicians. A First Outcome of the RESPACC Erasmus+ Project

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Background/aims: The RESPACC project aims to identify core research competencies as part of the general education related to clinical practice of Palliative Care (PC) clinicians. The notion of competence corresponds to the ability to apply knowledge and skills to successfully perform an activity at work. The aim of this work is to identify the required core research competencies of multidisciplinary PC teams, that will enable successful clinical research to be undertaken.

Methods: A multi-method 3 phase approach was adopted: I) A review of research competency frameworks; II) A Nominal Group Technique study eliciting the views of PC clinicians regarding clinical research; III) An international PC professional's consultation

Results: Eight competency research frameworks were identified and analysed as part of the literature review. Based on the TDR Global

Competency Framework for Clinical Research (TDR) (1), from the WHO, a structure of seven domains for a new framework for PC clinicians was adopted. Nominal Group Technique was utilised in three countries (Greece, Spain, and Romania). 31 PC clinicians generated 19 core competencies in seven domains. The 19 competencies identified during NGT meetings were compared to relevant frameworks in the literature and were adapted to the specific context of PC research. An international PC professional's consultation was undertaken to review and improve the framework. The survey was sent to 120 clinicians and 59 questionnaires returned, among which 53 were complete (response rate 44%, 17 countries) and, as a result, two competencies were eliminated and two rephrased. An additional recommendation on linguistic skills was added at the end of the framework.

Conclusions: New core research competencies for PC clinicians is offered in English, Spanish, Greek and Romanian. A self-administered quiz is being developed, as a tool to appraise the individual level of research literacy and competencies for clinicians working in PC.

Abstract ID: OA01:02

Abstract type: Oral Abstract

Validation of the Death Literacy Index in a Representative UK Sample

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Background/aims: A key construct within the public health approach to palliative care is 'death literacy'. Death literacy can be defined as 'the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and death care options'. The newly developed 29-item Death Literacy Index (DLI; Leonard et al, 2020) can be used to determine levels of death literacy across multiple contexts, including at a community/national level, and to evaluate the outcome of different public health interventions. The DLI is the first rigorously developed measure of the construct of death literacy, which is a key outcome for new public health approaches to palliative care (a priority public health area). The current study aims to provide the first validation of the DLI in a representative UK population sample.

Methods: A large nationally representative sample of 399 participants, stratified by age, gender and ethnicity, was prospectively recruited via an online crowdsourcing platform. The factor structure of the DLI was investigated using CFA. Internal consistency of subscales were assessed, alongside construct validity.

Results: Tests of dimensionality confirmed the original measure structure with substitution of one item. The subscales possess good internal consistency. Construct validity is currently being assessed to include convergent, divergent and known-group validity and will be presented.

Conclusions: The 29-item DLI will have application in evaluating new public health approaches to palliative care across the UK. This will help in addressing the dearth of formally evaluated interventions in this area, and potentially help inform service development.

Abstract ID: OA01:03

Abstract type: Oral Abstract

Validation of 'Care of the Dying Evaluation' (CODE™), a Post-Bereavement Tool, Within an International Context

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Background/aims: Measuring quality of care provided during the dying phase with validated instruments helps provide quality assurance and recognises areas of unmet need.

Study aim: to assess construct validity and internal consistency of 'Care Of the Dying Evaluation' (CODE™), a post-bereavement tool assessing quality of care in the last days, within an international context.

Methods: Post-bereavement survey (August 2017-September 2018) using CODE™; respondents next-of-kin to adult patients (≥ 18 years old) with cancer who had died an 'expected' death within the study site hospitals (n=22) in 7 countries: Argentina, Brazil, Germany, Norway, Poland, UK, Uruguay. Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA) conducted. Internal reliability assessed using Cronbach alpha (α). Known group validity assessed by ability to discriminate different perceptions in quality of care expected *a priori*. Hypotheses: perceptions would be higher in Palliative Care Units (PCUs) and in Poland (as most deaths occurred in PCUs within Polish hospitals). Differences were quantified using standardised effect sizes (SES).

Results: 914 CODE™ questionnaires completed (54% response rate). 527 (58%) male deceased patients; 610 (67%) next-of-kin female; most commonly 'spouse/partner' (411, 45%). EFA identified 4 factors: 'Overall care', 'Communication and support', 'Trust, respect and dignity', and 'Symptom management' with good reliability scores (α=0.628–0.862). CFA confirmed the 4-factor model but these were highly correlated and a bifactor model showed acceptable fit (Comparative Fit Index=0.962; root mean square error of approximation 0.057). The SES for quality of care in PCU's was 0.727; SES for Poland was 0.657. This is in keeping with *a priori* hypotheses of perceived higher quality of care and supports the sensitivity of CODE™ to detect differences.

Conclusions: Within an international context, CODE™ was found to be a valid, reliable tool for assessing the quality of care provided in the last days of life.

Abstract ID: OA01:04

Abstract type: Oral Abstract

Methodological Issues and Challenges in Designing and Conducting Research at the End of Life: Findings of Qualitative and Textual Evidence from Researchers Perspective

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Background/aims: Conducting research with patients facing end of life is ethically and methodologically complex. Dealing with these issues may be difficult while maintaining high-quality methodological studies. Reflecting critically about methodological issues in conducting research at the end of life is important to make researchers aware and prepared for difficulties they will confront. The purpose of this review was to identify all possible issues related to research with patients facing end of life.

Methods: 4 databases (MEDLINE, EMBASE, CINAHL, PsycInfo) were searched from inception until the end of 2020 for articles which reported on researchers' experiences conducting research with patients and their families at end of life. Qualitative studies, mixed-methods studies with a qualitative component and opinion-based papers were included and data from included studies were extracted using the Joanna-Briggs Institution meta-aggregation methodology.

Results: 16 out of 1983 identified studies met inclusion criteria. A total of 108 excerpts were initially extracted and grouped into 19 initial categories thought to broadly represent the ideas expressed in the extracted data. These categories were finally transformed into 6 themes: (1) the need for flexibility at all stages of the research process, (2) careful

attention to timing, (3) sensitivity in approach, (4) the importance of stakeholder collaboration, (5) the need for unique researcher skills and (6) the inevitability of loss emerged as core challenges and solutions expressed by researchers in the field.

Conclusions: This review highlighted the unique and complex methodological and ethical challenges faced by researchers conducting and designing studies with patients at end of life and the families who support them. The findings showed several specific requirements that should be reflected in training programs, ethical review processes and research designs.

This work was supported by an EU Joint Programme - Neurodegenerative Disease Research (JPNDR) project.

Abstract ID: OA01:05

Abstract type: Oral Abstract

Identifying Dutch Hospitalized Patients with a Limited Life Expectancy and Palliative Care Team Involvement: A Flashmob Study

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Background/aims: Many hospitalized patients have a life-limiting condition. It is not known how many patients this concerns and if these patients receive palliative care. This study aimed to investigate how many patients with a probable limited life expectancy were hospitalized and if a palliative care team (PCT) was involved or whether involvement was considered desirable.

Methods: A flashmob study was conducted in Dutch hospitals on the 16th of April 2021 at all wards, except the pediatric and obstetric wards, emergency departments and day care departments. For all hospitalized patients, nurses and doctors independently answered the surprise question (SQ) "Would you be surprised if this patient died within the next 12 months?" as well as treatment limitations and palliative care team (PCT) involvement.

Results: In 48 hospitals, surveys were completed for 8789 patients. Patients were admitted to surgical wards in 33% and to general medicine wards in 67%. The SQ was negatively answered in 35% by doctors and in 32% by nurses for the total population. Among patients admitted for a malignancy, non-malignant disease or COVID-19 doctors answered the SQ negatively in 49%, 32% and 33% respectively. Life expectancy was estimated to be less than three months in 7.3% for the total population. Treatment limitations were recorded in 39.5% of the total population. The PCT was involved in 2.2% and involvement was desirable in 2.1%, increasing to 15.1% and 12.9% when life expectancy was estimated as less than three months.

Conclusions: In more than one-third of hospitalized patients, the SQ was answered negatively, suggesting a limited life expectancy and possible palliative care needs. PCT involvement was considered of added value by healthcare professionals in 4.3% of the whole population. Further studies should focus on exploration of palliative care needs of hospitalized patients and possible benefits of timely implementation of specialized palliative care.

Cancer

Abstract ID: OA02:01

Abstract type: Oral Abstract

Stakeholder Involvement in Formulation of Guideline Questions: Findings from the AINO/SICP/SIN Guidelines on Palliative Care in Adults with Glioma

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Background/aims: In 2017, the European Association for Neuro-Oncology (EANO) published the guidelines for palliative care (PC) in adults with glioma. The Italian Society of Neurology (SIN), the Italian Association for Neuro-Oncology (AINO) and the Italian Society for Palliative Care (SICP) joined forces to update and adapt these guidelines to the Italian context; and (herein presented) to involve patients, caregivers and health professionals (HPs) in the formulation of the clinical questions.

Methods: We used a mixed methods approach, which encompassed a HP web survey, interviews with patients with glioma, and focus group meetings (FGMs) with bereaved caregivers (CG). Participants rated the importance of 14 pre-specified intervention topics produced by the guideline panel, and suggested additional topics.

Results: Of 244 survey participants, 149 (61%) were PC HPs and 95 (39%) neuro-oncology (NO) HPs. Mean age was 48.9 years, 152 (63%) were women, and 48% had over 12 years of experience in the care of glioma patients. Physicians were 166 (68%), followed by nurses (28%), psychologists (7%), therapists (3%), and social workers (2%). Symptom management, psychosocial support, and early PC received the highest ratings. Main differences between PC and NO HPs were for spiritual/existential support, bereavement, ACP and end of life care. We interviewed 20 patients (14 men; median age 59; median disease duration 2 years), and held five FGMs with 28 caregivers (6 men; 16 spouse or partners). Communication and psychological support, changes in cognitive functions, mood and personality were the most discussed themes by both patients and CG. Role of early PC was unclear though considered important, and lack of knowledge of Italian laws on ACP emerged.

Conclusions: All the stakeholders confirmed the importance of the 14 intervention topics, with no additional topics identified. Interviews with patients and particularly the FGMs with caregivers were emotionally taxing, albeit focused.

Abstract ID: OA02:02

Abstract type: Oral Abstract

Experiences and Perspectives of Patients with Advanced Cancer and (Healthcare) Professionals Regarding Work Resumption and Retention

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Background/aims: Being able to work improves the quality of life of patients with cancer. Yet, studies focusing on the experiences of patients with advanced cancer who want to return to work or stay employed are scarce. We aimed to explore the perceptions of patients with advanced cancer and (healthcare) professionals regarding work resumption and work retention and the barriers and facilitators they may experience

Methods: Semi-structured interviews were conducted with patients with advanced cancer and relevant (healthcare) professionals. Participants were recruited through medical specialists and patient organisations. Interviews were transcribed and analysed using ATLAS.ti by means of the thematic analyses

Results: Fifteen patients with advanced cancer (87% female, mean age 52) were interviewed. Paid employment was still an important issue in their lives. Social discomfort of the environment, regarding undergoing palliative treatment and (return to) work, and non-tailored laws and regulations necessitated patient-initiated communication and a proactive attitude. Interviews with seventeen (healthcare) professionals (65% female; mean age 52 years) with different occupations were held. Preconceptions and reluctance towards work reintegration and retention of these patients were identified.

Conclusions: While most (healthcare) professionals are open to return to work and work retention for patients with advanced cancer, there are several barriers to overcome due to the lack of specific knowledge and experience. The findings of this study might correct erroneous preconceptions about the work ability of advanced cancer patients. Clarity about responsibilities and experience with legislation could create opportunities for successful work retention. Guidelines should be developed for occupational reintegration of patients with advanced cancer.

Abstract ID: OA02:03

Abstract type: Oral Abstract

Reducing Emergency Department Use for Ambulatory Oncology Patients Requiring Palliative Care: A Quality Improvement Initiative

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Background/aims: At the Odette Cancer Centre in Toronto, Canada, almost 1 in 5 ambulatory palliative oncology patients presents to our local Emergency Department (ED) every month. Of these visits, approximately 50% are potentially avoidable as they result in a direct discharge home, or in an acute care admission of < 48 hours. For a palliative cancer patient, ED visits are frustrating, costly and are considered an indicator of poor-quality end-of-life care. To improve end-of-life care for this vulnerable population, reducing ED visits is imperative.

Methods: We conducted an interrupted time series following the Model for Improvement with an aim to reduce the monthly ED visit rate for the patients of our oncology palliative care clinic by 20% over 1 year. A patient-informed root cause analysis was performed to guide the implementation of a bundle of three change concepts:

- (1) improving patients' after-hours access to hospital and home care
- (2) increasing video virtual visits; and (3) enabling early identification of caregiver burnout.

Results: Monthly ED visit rates declined by 24% ($p < 0.001$) with evidence of sustained improvement. The percentage of ED visits that resulted in a hospital admission of < 48 hours remained unchanged. Fidelity was attained by the interventions associated with the first change concept.

Conclusions: Improving patients' after-hours access to hospital and home care was associated with a clinically and statistically significant reduction in ED visits. This is the first study in the palliative oncology population to implement patient-informed interventions to reduce ED use. The study occurred during the COVID-19 pandemic which constitutes a significant confounding factor. Continued evaluation post-pandemic will serve to better understand ongoing trends in ED use.

Abstract ID: OA02:04

Abstract type: Oral Abstract

Cognitive Concerns, Illness Intrusiveness, and Quality of Life in Patients with Brain Metastases

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Background/aims: Brain metastases occur in approximately 30% of cancer patients, affecting quality of life (QOL) and cognitive function. In this study we surveyed patient- and caregiver-reported cognitive concerns, emotional well-being, QOL, and supportive care needs to address cognitive concerns; and whether illness intrusiveness (i.e., the extent to which disease and/or treatment interfere with valued activities and interests) mediated the relations between cognitive concerns and emotional well-being and QOL.

Methods: 109 brain metastasis patients and 38 caregivers completed validated questionnaires examining cognitive concerns (FACT-Cog v3), emotional well-being (HADS), and QOL (FACT-G), and a supportive care needs survey. Hierarchical multiple-regression analyses tested whether illness intrusiveness mediated the effect of cognitive concerns on emotional well-being and QOL.

Results: Clinically significant cognitive concerns were reported by 15.7% of patients and 23.7% of caregivers; patients and caregivers expressed similar needs for information and strategy training (means 8.1-8.2 out of 10) to manage these concerns. Greater cognitive concerns weakly correlated with greater illness intrusiveness ($\beta = -0.18$, 95%CI [-0.36, 0.0048], $p = 0.05$), and illness intrusiveness significantly correlated with worse emotional well-being ($\beta = 0.45$, 95%CI [0.25, 0.65], $p < 0.001$). Illness intrusiveness also significantly correlated with worse QOL ($\beta = -0.54$, 95%CI [-0.76, -0.32], $p < 0.001$). These suggest the possibility of a mediated effect between cognitive concerns and emotional well-being, and between cognitive concerns and QOL.

Conclusions: Cognitive concerns were associated with reduced emotional well-being and QOL in brain metastasis patients, mediated in part by illness intrusiveness. With the need for supports to address cognitive concerns, targeted interventions should include efforts to help patients remain engaged in valued activities and interests to help preserve QOL.

Abstract ID: OA02:05

Abstract type: Oral Abstract

Surprise Question and Performance Status Indicate Urgency of Palliative Care Needs in Patients with Advanced Cancer at the Emergency Department: A Cohort Study

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Background/aims: The surprise question (SQ), 'Would I be surprised if this patient died within 1 year?', is a simple instrument to identify patients with palliative care needs. The SQ-performance in patients with advanced cancer visiting the emergency department (ED) is unknown. Aim of the study was to evaluate SQ's test characteristics and predictive value in patients with advanced cancer visiting the ED.

Methods: Cohort study May 2013 - July 2014 in patients >18y with advanced cancer in the palliative phase visiting the ED of an academic medical center. Follow-up was updated until February 2019. Attending physicians answered the SQ (not surprised (NS) or surprised (S)) and estimated ECOG-performance status. Disease, visit and follow-up characteristics were retrospectively collected from charts. SQ's sensitivity, specificity, positive (PPV) and negative predictive values (NPV) and

Harrell's c-index were calculated. Prognostic values of SQ and other variables were assessed using Cox proportional hazards models.

Results: Two-hundred-and-forty-five patients were included (203 NS (83%) and 42 S (17%)), median age 62 years, 48% male. Follow-up on overall survival was updated until February 2019. At ED-entry, NS-patients had worse ECOG-performance and more symptoms. At study closure, 233 patients had died (95%). Median survival was 3.0 months for NS-patients (IQ-range 1-8); 9.0 months for S-patients (IQ-range 3-28) ($p < 0.0001$). SQ-performance for 1-year mortality: sensitivity 89%, specificity 40%, PPV 85%, NPV 50%, c-index 0.56, HR 2.1 for approaching death. ECOG 3-4 predicted death in NS-patients; addition to the SQ improved c-index (0.65); sensitivity (40%), specificity (92%), PPV (95%), NPV (29%).

Conclusions: At the ED, the SQ plus ECOG 3-4 helps identifying patients with advanced cancer and a limited life-expectancy. Its use supports initiating appropriate care related to urgency of palliative care needs.

Symptom Management

Abstract ID: OA03:01

Abstract type: Oral Abstract

An Observational Study of the Use of 48-hour Continuous Subcutaneous Infusions in a Community Specialist Palliative Care Setting

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Background/aims: Continuous subcutaneous infusions (CSCIs) are used by specialist palliative care teams to administer multiple drugs simultaneously to optimise symptom control at end of life care and when the oral route is compromised. Current practice denotes that a CSCI infuses over 24 hours. Anecdotal evidence suggests that CSCIs infusing over 48 hours are being used in a community specialist palliative care setting. Review of the literature reveals a scarcity of data pertaining to the effectiveness and safety profile of 48-hour CSCI utilisation.

Methods: A retrospective observational study of 48-hour CSCI usage by a community specialist palliative care team between July 2016 and December 2019 was carried out. Data from the community palliative care team records including medication doses, drug combinations, reported complications and patient demographics was collected and analysed.

Results: 71 patients prescribed 48-hour CSCIs were included in the study. The majority of patients had a malignant diagnosis ($n=57$). Reason for CSCI commencement was end of life care ($n=43$) or symptom control ($n=28$). Median duration of 48-hour CSCI was 4 (range 1-36) days. All infusions contained two or more medications; dexamethasone 0.5mg was included in 85% ($n=61$). The most commonly prescribed medications included levomepromazine ($n=59$), midazolam ($n=52$) and morphine sulphate ($n=51$). Four site issues were encountered. No adverse events were identified.

Conclusions: These results provide evidence that 48-hour continuous subcutaneous infusions have been used safely and effectively to administer medications in a community palliative care setting. Utilisation of 48-hour CSCIs will benefit patient care and impact favourably on healthcare resources. Ongoing research will add to the limited evidence base available.

Abstract ID: OA03:02

Abstract type: Oral Abstract

Prognostic Indicators in Cancer Pain: Towards an Improved Classification System

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Background/aims: This is a prospective observational study of patients with chronic, moderate to severe cancer pain, receiving strong opioids. Our aim was to identify baseline prognostic factors, exploring the association between pain intensity during follow-up and pain syndromes, adjusting for patients' characteristics.

Methods: The evaluation of the pain syndrome and pain characteristics was performed at baseline. All patients were followed-up for a period of 28 days. A mixed model was built to evaluate the association between average mean pain intensity during follow-up (AvPI) and clinical prognostic factors. We analyzed data from 342 enrolled patients who had at least one follow-up visit.

Results: Mean AvPI at baseline was 5.4 (± 1.4). Pain intensity decreased significantly for all patients during each time point ($p < 0.001$). Age, sex, emotional distress, pain duration and a positive DN4 questionnaire were not significantly associated to AvPI. Breakthrough pain (BTP) was related to higher pain intensity during follow-up ($\beta=0.55$, $p < 0.001$). Overall, the presence of pain syndromes (alone or in combination) was significantly associated to AvPI ($p=0.029$). In particular, the concurrent presence of visceral and soft ($\beta=1.02$, $p=0.026$) or soft and nervous tissue pain ($\beta=0.67$, $p=0.043$) were significantly related to worse outcome, whereas pain due to only soft tissue damage was associated with better outcome ($\beta=-0.49$, $p=0.032$).

Conclusions: The early recognition of prognostic factors, such as presence of BTP and specific pain syndromes may help in providing better classification and management of cancer pain patients.

Abstract ID: OA03:03

Abstract type: Oral Abstract

A Feasibility Cluster Randomised Controlled Trial of Paramedic-Administered Breathlessness Management Intervention for Acute-On-Chronic Breathlessness (BREATHE): Study Findings

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Background/aims: One-fifth of conveyances to the emergency department (ED) are due to acute-on-chronic breathlessness. Paramedic breathlessness management may ease distress quicker and/or reduce ED conveyances.

We evaluated the feasibility of a full trial of a paramedic delivered intervention to reduce avoidable conveyances (recruitment, randomisation, consent, training and intervention acceptability, adherence, data quality, best primary outcome, sample size estimation). The intervention comprised evidence-based non-drug techniques and a self-management booklet.

Methods: This mixed-methods feasibility cluster randomised controlled trial (ISRCTN80330546) with embedded qualitative study about trial processes, training and intervention delivery, randomised paramedics to usual care or to intervention + usual care. Retrospective patient consent

to use call-out data and prospective patient/carer consent for follow-up was sought. Potential primary outcomes were breathlessness intensity (numerical rating scale) and ED conveyance. Follow-up included an interview for patients/carers and questionnaires at 14 days, 1 and 6 months and paramedic focus groups and survey.

Results: Recruitment was during the COVID-19 pandemic, leading to high demands on paramedics and fewer call-outs by eligible patients. We enrolled 29 paramedics; 9 withdrew. Randomisation and trial procedures were acceptable. Paramedics recruited 13 patients; 8 were followed up. Data quality was good. The intervention did not extend call-out time, was delivered with fidelity and no contamination and was acceptable to patients, carers and paramedics. There were no repeat call-outs < 48 hours. Recruitment stop-go criteria were not met. We had insufficient data for sample size estimation.

Conclusions: A full trial in the same circumstances is not feasible. However, valuable information was gained on recruitment, attrition, consent, training and intervention acceptability and adherence, and patient-reported data collection.

Abstract ID: OA03:04

Abstract type: Oral Abstract

Cancer Cachexia: A Scoping Review on Non-Pharmacological Interventions

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Background/aims: Cancer cachexia (CC) occurs in 30-80% of patients, increasing morbidity, mortality and impacting health-related quality of life (QoL). Up to now, it remains an unmet clinical need: various pharmacological interventions have been studied, showing inconsistent effects on appetite, QoL, and many drop out in trials due to lack of compliance. We aim to provide an overview of available evidence on non-pharmacological interventions for CC.

Methods: Based on PRISMA-ScR, we conducted a scoping review of empirical studies, searching MEDLINE, Embase, Cinhal, Cochrane, Psycinfo, and Scopus, from inception to March 2021. The search keywords were: (cachexia OR anorexia) AND (cancer OR tumor OR neoplasm OR oncol*). Based on the definition of pharmacological intervention as “any substance that can produce functional modification, through a chemical and/or physical action”, we excluded all the studies that contained drugs, artificial nutrition, oral nutritional supplements, and fortified foods.

Results: The search retrieved 4282 articles, of which 17 were considered eligible. The preliminary data showed heterogeneity in populations and interventions, most of which were multimodal (28%). RCT was the most used study design (65%). Non-pharmacological components, alone or combined with others, were nutritional counseling, complementary therapies (e.g., acupuncture), rehabilitation, and psychotherapeutic interventions. The most common primary outcomes were body weight and body composition, biomarkers, QoL, psychological questionnaires, muscular strength.

Conclusions: This scoping review shows a varied landscape: small and heterogeneous samples, different settings, different disease localization and stage. Most of outcomes as laboratory or nutritional parameters often don't answer the real needs of patients. A personalized treatment approach to CC is necessary to ensure the best possible adherence to the therapeutic proposal and meet patient's physiological and psychological needs.

Abstract ID: OA03:05

Abstract type: Oral Abstract

Randomised Double-Blind, Placebo-Controlled Phase III Trial of Oral Melatonin for the Prevention Of Delirium in Hospital in People with Advanced Cancer

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Background/aims: Delirium is highly prevalent in advanced cancer. Delirium causes significant symptom burden, high levels of patient and carer distress, morbidity, and mortality. Non-pharmacological delirium prevention strategies may be unachievable for some people with advanced cancer so alternative strategies are needed. Melatonin has shown promise as a safe preventative agent in other populations. The primary objective was to determine if oral prolonged release melatonin compared to placebo can increase the number of delirium-free days during hospitalisation of advanced cancer patients.

Methods: Prospective, randomised, double-blind, placebo-controlled, parallel-arm, multicentre phase III trial of oral prolonged release melatonin 2mg versus placebo taken each night during inpatient oncology or palliative care admission commenced within 48 hours of admission. Participants were adults with a diagnosis of advanced cancer who did not have delirium on admission and could take medication orally. The primary endpoint was delirium-free days. Delirium was defined as a Delirium Rating Scale-R-98 score of 17.75 or more.

Results: The study recruited to its full sample size (melatonin arm n=110, and control n=111) (mean age 68.8 years, 50.7% male). The majority (84.5%) had been admitted for symptom control. Median delirium free survival was not reached (95% Confidence Interval 28 - not reached). The mean (SD) delirium free days in the melatonin arm was 13.4 days (45.3) and in the placebo arm 11.7 days (35.1) (p=0.75).

Conclusions: Delirium free days were higher in those who received melatonin, but this did not reach statistical significance. Further studies are needed to explore whether benefits are seen in selected higher risk patient groups or with higher doses.

End-of-Life and Ethics

Abstract ID: OA04:01

Abstract type: Oral Abstract

Home Becomes the Most Common Place of Death for Cancer Patients During the COVID-19 Pandemic, A Descriptive Analysis in England

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Background/aims: Despite increased numbers of deaths in England from COVID-19 and its co-lateral effect on acute services (569,700 in 2020 vs. 496,370 in 2019) the number of deaths from cancer was virtually unchanged (138,026 in 2020 vs. 137,851 in 2019). Deaths (all causes) at home have exceeded the expected number every week since April 2020, (155,815 (27.4% of all deaths) in 2020 vs. 120,467 deaths (24.3% in 2019). Cancer deaths accounted for 35.5% of all deaths at home in 2019.

Aims: to investigate the contribution made by cancer patients to the increased deaths at home during the COVID-19 Pandemic in England.

Methods: National Mortality data used to identify cancer deaths (underlying cause) and place of death in England in 2019 and 2020 and compared for place of death as a proportion of all cancer deaths.

Results: Cancer increased as a % of all deaths in patients' own home in 2020 36.5% to 35.5%.

The % of cancer deaths in hospital reduced significantly from 35% to 29% and increased in patient's home from 31% to 41%. Reductions in % cancer deaths occurred in Care Homes 15% to 13%), Hospice 8% to 15% but an increase in other places (relatives homes) 1.7% to 2.4%. Thus a 19% reduction in cancer deaths in hospital, 15% reduction in hospices but 33% increase in homes.

Conclusions: In England, national strategy, improving choice of place to die achieved an 8-year 2011-19 small increase in cancer patients dying at home (28.9 to 31.1%). The COVID-19 pandemic caused a massive shift in the proportion of cancer patients (11%) and actual numbers (~15,000) dying in their own or relatives private homes. It is not clear how much of this change was forced decisions (hospitals full of COVID-19, Hospice beds reduced) or personal choice influenced by severe visiting restrictions in hospital, care homes and hospices. The quality of care provided is also not known. If choice played a significant role, and the current increase is sustained, community palliative care needs to be increased to support more cancer patients to die at home.

Abstract ID: OA04:02

Abstract type: Oral Abstract

Patients Who Die in Hospice Within Three Days After Admission: Can These Admissions be Prevented?

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Background/aims: In the Netherlands, people with a life expectancy of up to three months can be admitted to hospice. It is not uncommon that patients die within a few hours or days after admission. A transfer in the last days or hours of life can be very stressful and therefore it can be questioned if this can be avoided. The aim of this study is to gain insight in the characteristics of patients who die within 72 hours after admission to the hospice and in the reasons for referral.

Methods: Between April 2020 and October 2021, data were collected about 83 patients who died within 72 hours after admission in 4 hospices in the southwest of the Netherlands. Hospice nurses or physicians filled in a checklist (n=83) about the health status of the patient at admission, and asked the referring physician for additional information (n=70).

Results: Fifty-five percent of patients were female, the average age was 75 years and 53% were diagnosed with cancer. Main symptoms at admission were pain (53%) and dyspnea (48%). Patients were mainly referred from the hospital (65%). In 49% of cases, the hospice physician had expected death within three days at the patient's admission. In 34%, the referring physician had recognized that the patient was in the dying phase. In some of these cases there were specific reasons to transfer patients, such as the explicit wish of the patient and family (33%) or overload or absence of informal caregivers (29%). However, in 27% of all cases the referring physician had not recognized the dying phase, whereas the hospice physician had.

Conclusions: Death within three days cannot always be predicted, nor by hospice physicians nor by referring clinical specialists or GP's. In some cases referring physicians provided explicit reasons to transfer the patient to hospice. However, in about quarter of all cases, death with

three days was foreseen by the hospice physician but not by the referring physician. In these cases, admission to hospice could possibly have been prevented.

Abstract ID: OA04:03

Abstract type: Oral Abstract

♪ Ch-ch-ch-changes ♪ - Towards a New EAPC Guideline on Palliative Sedation

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Background/aims: The European Association of Palliative Care (EAPC) has published a framework on palliative sedation (PS) in 2009. This publication can be considered as a milestone in the debate on PS. However, more than a decade later a revision is needed considering new evidence from literature and to update the consensus among experts and stakeholders in this field.

Aim: To revise and update the 2009 EAPC framework on PS.

Methods: 4-step consensus procedure: 1. Breaking down the EAPC framework into its main components (2 researchers and steering group (n=6, ♀3)) and online-survey (SoSci) among international expert group (accepted n=30, 12♀, of n=33 invited) on applicability/need for revision for each of the resulting statements (07-09/2020). 2. First Delphi round among a larger group of international experts (Delphi panel; accepted n=91, 39♀; of n=193, 100♀ invited) using a five-point Likert scale on agreement plus free-text entry fields (04-06/2021). 3. Second Delphi round (11-12/2021). 4. The revised draft will be sent again to the members of the expert group and the steering group for a final review.

Results: Adjusted RR: expert group (100%); Delphi panel (97%). During the consensus procedure leading up to the 1st Delphi round, 4 statements and 2 observational tools were added to the framework, which was initially broken down into 38 components including a table of medication and 2 observational tools. In the 1st Delphi round, high consensus (measured by median, IQR and % of agreement) was reached, so that only 16 statements will be presented in the 2nd round.

Conclusions: The 4-step procedure with 2 Delphi rounds ensures an update of the EAPC framework on PS considering the expertise of experts and stakeholders from all over Europe (and beyond). Quantitative and qualitative results of both rounds will be presented.

Funding: This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825700

Abstract ID: OA04:04

Abstract type: Oral Abstract

The Use of Nudges in Physician-Patient Discussions about the Relevancy of Life-Sustaining Treatments

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Background/aims: “Nudges” refer to strategies which influence patients’ health decisions through the way information is presented. The use of nudges by healthcare professionals is sometimes ethically debatable, in particular when discussing sensitive topics with their patients, such as the decision for life-sustaining treatments (LST) or allowing for natural death. The aim of our study was to examine when and how physicians use nudges in such circumstances.

Methods: A collection of 43 audio-recordings of hospital admission encounters during which physicians discuss LST with older patients was examined to identify nudges; identified sequences were analysed through Conversation Analysis.

Results: We identified 4 types of nudges that physicians use:

- (i) designing their request for the patient’s preference to convey expectations about the decision (“You don’t want to be resuscitated, right?”);
- (ii) using social comparison to identify the most reasonable decision (“Patients say “no future care”);
- (iii) using pejorative descriptions of LST (“Do you want everyone to jump on you and resuscitate you”);
- (iv) structuring the conversations in a certain way, e.g., sharing information about personal prognosis after the patient expressed their preference.

In certain situations, the use of nudges leaves little place for the patient to engage in decision making, disagree or ask for information. Physicians use nudges particularly when they have reason to think that LST is not medically indicated for a patient.

Conclusions: Communication research contributes to a better integration of ethics into decision-making by identifying practices with a nudging potential. The ethicality of nudging is questionable when it exerts pressure on patients’ conformity without fully understanding why. Better communication training is needed in order to avoid such biases and support informed decisions.

Funding: This study was funded by a Swiss private institution.

Abstract ID: OA04:05

Abstract type: Oral Abstract

What are Patients’ Motives for Requesting Euthanasia? A Cross-Sectional Survey among Attending Physicians

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Background/aims: Physicians regularly treat or deal with patients requesting euthanasia in jurisdictions where this practice is legal. Little is known about the motives that lie behind patients’ euthanasia requests. A better understanding of their motives is pivotal in identifying and effectively addressing palliative care and support needs of these patients. This study aimed to examine the motives of patients who had requested euthanasia to their attending physicians.

Methods: A cross-sectional survey was conducted in 2019-2020 in Belgium among attending physicians of patients requesting euthanasia (N=904), who had consulted a physician trained in palliative care and assessing euthanasia requests by Life End Information Forum (LEIF).

Results: Response rate was 56%. Cancer was the main diagnosis in 57% of the patients, general deterioration in 15%, neurological disorder in 8%, and other diagnosis in 21%. In 19% attending physicians did not indicate suffering without prospect of improvement (a legal criterion) as their patient’s motive for requesting euthanasia. Tiredness of life and not wanting to be a burden on the family were motives in 28% and 26% respectively. In half of the patients, suffering without prospect of improvement was indicated as

the most important motive for requesting euthanasia, and in about 1 out of 10 patients loss of dignity (11%), pain (9%), or tiredness of life (9%) was reported. 79% of patients received euthanasia; general weakness or fatigue, loss of dignity, and loss of independence in daily life were associated with a higher likelihood of receiving euthanasia. Depression as a motive was associated with a lower likelihood of receiving euthanasia.

Conclusions: One in five euthanasia requests did not result in its performance. For these patients, palliative care should provide specialized support tailored to their personal needs. Paying attention to psycho-social and existential suffering is especially important as many motives are related to it.

COVID-19

Abstract ID: OA05:01

Abstract type: Oral Abstract

Palliative Care Should be Part of a Public Health Pandemic Response – How Routine Data Analysis in the COVID-19 Pandemic in England Could Inform Level of Need and Deployment of Services

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Background/aims: Palliative and End of Life Care (P&EOLC) services normally have a relatively fast turnover of patients, however, the monthly numbers in any setting/geography is usually predictable. In the COVID-19 pandemic there was a seismic rise in the number dying (in England, 494,611 (2019), 568,070 (2020) and 321,474 (2021 January to July). Deaths peaked in the 1st and 2nd waves.

Aims: To describe the temporal changes in demand for P&EOLC services during the pandemic and geographical variation in impact on provision in different settings.

Methods: Mortality data for England, January 2019 to July 2021 was analysed by calendar month, place of death, and geographically for 106 clinical commissioning groups (CCGs) = health administrations. Comparisons were made for 2020 and 2021 with reference to 2019. For 2021 the data January to July was compared to these months in 2019. The variations across CCGs were described using interquartile range (IQR).

Results: In 2020 deaths increased by 15% (73,459) vs. 2019 and 10% (29,652) more in 2021 (Jan to July) c.f. 2019. 2020 saw increases in deaths of: 29% (35,342) at home, 21% (23,281) in care homes, 7% (15,970) in hospital but -12% (3,470) in hospice. April 2020 (peak of first wave) showed the greatest change by month: of: 194% (17,732) care home, 86% (8,428) home, 84% (15,629) hospital, but -6% (150) in hospice. Across 106 CCGs in 2020 variation in increase in deaths had IQR: care home (14% to 29%), home (23% to 34%), hospital (2% to 13%), hospice (-23% to -4%). In April 2020 across 106 CCGs the variation in deaths had an IQR: care home (137% to 275%), home (58% to 105%), hospital (46% to 96%), hospice (-27% to 17%).

Conclusions: These results emphasise the importance of joint working in a pandemic to mobilise the public health response and P&EOLC services to use data to mobilise expert P&EOLC support to organisations and geographies with greatest need. Rapid P&EOLC redeployment is key and new ways of working (phone/video) to support/train non-specialists to support the dying.

Abstract ID: OA05:02

Abstract type: Oral Abstract

The Impact of COVID-19 on the Provision of Voluntary and Community Sector Bereavement Services: A Cross-Sectional Survey from the UK

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Background/aims: During the COVID-19 pandemic, voluntary and community sector (VCS) bereavement services including hospices have played a central role in supporting the bereaved. We aimed to describe the impact of the pandemic on these services to inform service development and policy.

Methods: Cross-sectional online survey of VCS bereavement services in the UK, open March-May 2021, disseminated via national organisations, associations and networks, and social media.

Results: 147 organisations participated; 53% were regional, 16% UK-wide. 36% were hospice or palliative care services, 15% national bereavement charities or NGOs; 12% local bereavement charities. During the pandemic referrals increased for 46% of organisations and decreased for 35%. 40.3% reported a current waiting list >3 weeks. 78.2% had changed services due to Covid; 51.7% introduced new services. There had been a significant reduction in provision of all face-to-face support including peer group meetings (50% to 4.1%, OR 0.04), facilitated group meetings (78% to 11%, OR 0.04), 1:1 support (87% to 27%, OR 0.06) and specialist intervention (44% to 16%, OR 0.25). Online and telephone provision saw major increases, particularly online 1:1 support (8.8% to 83%, OR 50.3), facilitated group meetings (4.1% to 56%, OR 30.48) and specialist intervention (3.4% to 36%, OR 16.01). Challenges included staff/volunteers providing support from home (69/64%), emotional impact on staff/volunteers (67/41%), increased pressure on staff due to client volume (41%) and complexity of needs (44%), implementing staff training (60%) and financial challenges (53%). 93% reported positive changes/opportunities during the pandemic, e.g., new coordination initiatives (47%).

Conclusions: UK bereavement services rapidly transformed during the pandemic, despite significant challenges. To ensure positive changes and innovations are retained, the experiences and acceptability of new and adapted services among clients and staff require further investigation.

Abstract ID: OA05:03

Abstract type: Oral Abstract

Taming Wicked Problems – Structure and Process Characteristics of Specialist Palliative Care During the COVID-19 Pandemic

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Background/aims: The provision of effective palliative care is highly important, yet especially challenging in the context of the current COVID-19 pandemic. Individuals, society, politics, and obviously specialist palliative care (SPC) are affected by the rapid spread of the virus and extensive countermeasures. The concept of ‘wicked problems’ relates to complex issues without precedent and proven resolutions and can be used to analyze the aftermath of the pandemic on SPC. We aimed to explore the impact of the COVID-19 pandemic on structures and processes in SPC in Germany.

Methods: Qualitative study across Germany, following a constructivist grounded theory methodology, with 11 semi-structured expert interviews between May and July 2020 and 23 episodic interviews with healthcare professionals in SPC settings (including physicians, nurses,

therapists, pastoral care, and social work) between February and June 2021.

Results: The pandemic led to unique structural and processual challenges in SPC that correspond to the key characteristics of ‘wicked problems’ (e.g., complex interdependencies; contradictory factors or changing requirements). Thus, as typical for ‘wicked problems’, all attempts for solutions could possibly result in new problems or unknown negative consequences. However, creative strategy approaches and dynamic responsiveness at the meso- and micro-level contributed to innovative development and could enhance the implementation of long-lasting improvement within SPC services. Availability of information, transparent communication, comprehensible instructions as well as involvement and participation in decision-making and search for solutions were factors contributing to a proactive development of SPC teams over the course of the pandemic.

Conclusions: Addressing the ‘wicked problems’ in SPC caused by the COVID-19 pandemic requires system thinking and a learning mindset facilitating teams to overcome the pandemic and move forward rather than bounce back to normal.

Abstract ID: OA05:04

Abstract type: Oral Abstract

The Impact of COVID-19 on Palliative Care for Children Within the UK

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Background/aims: Children and young people (CYP) with life-limiting or life-threatening conditions (LLTC) represent a group with complex care needs that are met by multiple services and thus may be subject to particular vulnerabilities.

Aim: To explore the impact of the COVID-19 pandemic and lockdowns on CYP with LLTC and their families in the UK.

Methods: Sub-analysis of an emergent COVID-19 theme from a larger UK-wide semi-structured interview study investigating priority paediatric palliative care outcomes with key stakeholders (n=106 participants).

Results: COVID-19 was raised in 12/44 interviews conducted after the UK's first confirmed COVID-19 case.

CYP with LLTC and their families had to shield during lockdowns and faced additional challenges regarding service provision changes, appointment cancellation, delays in necessary home adaptations, and loss of both respite and in-home carers. This increased the workload of care on other family members and was compounded by loss of friend and family support networks, negatively impacting their psychological wellbeing. Many families were worried about COVID-19, but for CYP whose LLTC increased vulnerability to infection, this was intensified.

Conclusions: Continued delivery of child- and family-centred palliative care requires innovative assessment and delivery of psycho-social support. Disruptions within treatment and care providers may compound support needs, requiring co-ordination for families facing multi-agency delays.

Table 1. Demographic details of participants.

		N or median (range)	
Children and Young P (n=3)	Age (yrs)	14 (10-17)	
	Gender	Female:Male 2:1	
	Diagnosis	Cancer 2 Neurological 1	
Parent/carers (n=7)	Age (yrs)	53 (21-65)	
	Gender	Female:Male 3:4	
	Relationship to CYP	Father	4
		Mother	2
		Sibling Caregiver	1
	Diagnosis of CYP	Cancer	4
Congenital		2	
Neurological		1	
Paediatric Palliative Care Commissioners (n=2)	Age of CYP (yrs)	15 (0-17)	
	Gender	Female:Male 2:0	

Abstract ID: OA05:05**Abstract type:** Oral Abstract**Specialist Palliative Care Professionals' Experiences of Moral Distress during COVID-19: A Multiple Qualitative Case Study**

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Background: Internationally, COVID-19 has placed additional strain on already stretched health care systems. This has influenced how specialist palliative care organisations and their staff have been able to respond to clinical need in accordance with their professional values.

Aims: To explore how COVID-19 impacted specialist palliative care staff and how organisations responded to the impact of the pandemic on staff well-being.

Methods: Qualitative multiple case study, part of the CovPall study. Cases were English hospices providing specialist palliative care services in any setting. Semi structured interviews were carried out with hospice staff between 11/20-04/21, purposefully sampled by role, care setting and COVID-19 experience. Interviews were analysed using framework analysis.

Results: Five cases (n=24 participants). Infection control constraints (e.g., visiting restrictions, PPE) prohibited and diluted participants' ability to provide care that reflected their core values. This resulted in staff experiencing moral distress. Despite organisational, team, and individual support strategies to address staff well-being, continually managing these constraints led to a 'crescendo effect' in which the impacts of moral distress (e.g., sadness, guilt, frustration, and fatigue) accumulated over time, sometimes leading to burnout. Some gained 'moral comfort' from solidarity with colleagues and making a valued contribution.

Conclusions: This study provides a useful insight into why and how specialist palliative care staff experienced moral distress during COVID-19, and how organisations have responded. Despite their expertise in caring for the dying, staff well-being and mental health was affected by the pandemic. Prolonged experiences of moral distress has a detrimental impact on staff and the quality of care. Organisational, structural, and policy changes are urgently required to mitigate and manage these impacts.

Funding: Funded by UKRI/NIHR [COV0011; MR/V012908/1]

End-of-Life and Bereavement**Abstract ID:** OA06:01**Abstract type:** Oral Abstract**Inequalities in Access to Bereavement Support Before and During COVID-19: Findings from Voluntary and Community Sector Bereavement Services in the UK**

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Background/aims: The COVID-19 pandemic has resulted in global mass bereavement; in the UK alone there have been 140,000 deaths to date, with a disproportionate impact on Black, Asian or minoritized ethnic (BME) communities. Voluntary and community sector (VCS) bereavement services including hospices play an important role in bereavement support. We aimed to determine services' perspectives on access to their support.

Methods: Cross-sectional online survey of VCS bereavement services in the UK, open March-May 2021, disseminated via national organisations, associations and networks and social media.

Results: 147 organisations participated; 53% served specific counties or smaller regions; 16% were UK-wide. 36% were hospice or palliative care services, 15% national bereavement charities or NGOs; 12% local bereavement charities. 67.3% reported there were groups with unmet needs not accessing their services before the pandemic; most frequently reported were people from BME communities (49%), sexual minority groups (26.5%), deprived communities (24.5%) and men (23.8%). 50% of services reported that, in the year before COVID-19, <5% of clients were from BME communities; 25% did not collect this data and 25% reported >5% BME clients. Compared with before the pandemic, 3.4% of services were seeing more people from BME groups, 52% were seeing the same proportion, 6.1% were seeing fewer and 38% didn't know/didn't collect this data.

Conclusions: For over two thirds of VCS bereavement services in the UK, there are known inequities in who accesses support, with people from BME groups most likely to be recognised as needing support but not

accessing services. During the pandemic, the proportion of BME clients did not increase, despite these communities being disproportionately affected by COVID-19. More attention needs to be paid to assessing and meeting unmet needs for formal bereavement support among disadvantaged groups and routinely collecting client data to help determine and ensure equity.

Abstract ID: OA06:02

Abstract type: Oral Abstract

Understanding Community Anticipatory Medication Care: A Longitudinal Qualitative Interview Study with Patients, Informal Caregivers and Their Clinicians

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Background/aims: The prescription of injectable anticipatory medications (AMs) is a common end-of-life care intervention. Practice is largely based on clinicians' beliefs that the availability of AMs in the patient's home offers reassurance and effective control of symptoms. Patients and informal caregivers' views and experiences of AMs have been insufficiently studied.

Aim: To explore patients', informal caregivers' and clinicians' views and experiences of decisions to prescribe and use AMs

Methods: A multi-perspective, longitudinal, qualitative interview study based on 11 patient cases, with three month follow-up. Cases included 21 participants: six patients, nine informal caregivers and six clinicians. Semi-structured interviews (n = 28) were audio recorded in 2020 and analysed inductively using constant comparison and thematic analysis.

Results: Three themes were identified: 1) *"Living in the present whilst making plans"*: AMs were used as a practical tool in planning for uncertainty, whilst patients and informal caregivers tried to concentrate on living in the present; 2) *"Future images of dying"*: Discussion of the process of dying and the role of AMs in controlling symptoms was often vague, inadequate or even absent. Some patients and informal caregivers expressed ambivalence about AMs and perceived that they might hasten death; 3) *"Accessing appropriate care"*: Getting AMs administered posed a significant challenge for families, despite receiving assurances that drugs would be given when needed. Although administered AMs generally helped symptom control, some informal caregivers reported difficulties in persuading nurses to administer them to patients.

Conclusions: AMs are not as reassuring as the existing evidence suggests. Prescriptions need careful discussion and tailoring to the preferences and experience of patients and families. Nurses' decisions to administer medication should consider informal caregiver insights into patient distress, especially when patients can no longer communicate.

Abstract ID: OA06:03

Abstract type: Oral Abstract

How do you Develop International Core Outcomes for Care of the Dying? A Delphi Study to Gain Consensus on the Content of the 10/40 Model for Best Care of the Dying Person

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Background: The 2013 publication by Ellershaw and Lakhani 'Best Care for the Dying' defined good care at the end-of-life as being able to die in

the place of our choice, free from pain, cared for with dignity and supported by the best possible care, and identified 10 key elements for care of the dying. These key elements were used to underpin the development of the 10/40 Model for Best Care of the Dying Person. Utilising expert opinion, the 10/40 Model operationalised the '10 Key Principles' to include '40 Core Outcomes' to support high quality care at the bedside.

To ensure that the 10/40 Model represents best available evidence and expert opinion, it was necessary to review the Model as part of a quality improvement cycle.

Aim: Gain international consensus on what constitutes best care for the dying.

Objectives: Assess the relevance and applicability of the 10 key principles and 40 core outcomes in the 10/40 model

Incorporate the latest research evidence in to the 10/40 Model

Make recommendations for amendments if required

Gain International agreement on the content of the 10/40 Model

Methods: A Delphi study was conducted, using iterative rounds of questionnaire completion; each round informed the need for, and content of the next. Round 1 assessed levels of agreement for each of the 10 Key Principles and 40 Core Outcomes, using a 5-point Likert scale (0 – low agreement; 5 – very high agreement), and included free text boxes for comments and suggestions for amendment/additions.

Results: Three rounds of Delphi were undertaken. 160 participants took part in Round 1, representing 30 countries; 103 in Round 2, 57 in Round 3. Agreement was reached for the content of the 10/40 Model, with minor amendments made to 2/10 Key Principles and 5/35 Core Outcomes.

Conclusions: Agreement was reached on what constitutes best care for the dying. The updated 10/40 Model continues to promote the delivery of high-quality end-of-life-care that can be provided to any patient regardless of diagnosis or place of care.

Abstract ID: OA06:04

Abstract type: Oral Abstract

Grief, Support Needs and Associated Factors Among People Bereaved During the COVID-19 Pandemic: Baseline Results from a Longitudinal UK Online Survey

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Background/aims: The COVID-19 pandemic has had a detrimental impact on millions of people's experiences of bereavement. Traumatic end-of-life experiences and disruptions to support networks increase chances of poor bereavement outcomes. We aimed to examine grief and support needs, and identify associated risk factors.

Methods: Mixed-methods survey of people bereaved in the UK from Mar 2020-Jan 2021, disseminated via media, social media, national associations, community/charitable organisations. Practical and emotional support needs were assessed in 13 domains, and grief intensity using the Adult Attitude to Grief (AAG) scale, which calculates an overall index of vulnerability (IOV) (range 0-36).

Results: 711 participants, mean age 49.5 (SD 12.9); 88.6% female; 95.3% white. Mean age of deceased 72.2 (SD 16.1); 58% died in hospital; 44% from COVID-19. Mean IOV was 20.41 (95% CI = 20.06 to 20.77), i.e., high vulnerability in grief overall. 28.2% exhibited extreme

levels of vulnerability (i.e., IOV \geq 24). In six support domains, all relating to psycho-emotional support, 50% to 60% of respondents reported high/fairly high levels of need. Increased levels of perceived support from health professionals led to significantly ($P < 0.001$) lower levels of grief and support need (small/medium effect, $P < 0.001$). Bereaved participants who were socially isolated/lonely experienced higher levels of grief and support needs than those who were not ($P < 0.001$). Grief and support needs were much higher for close family members compared with other groups ($P < 0.05$). Levels of grief and support needs were slightly higher for COVID-19 deaths compared with non-COVID-19 ($P < 0.01$), although this was not significant in a mixed model. **Conclusions:** People bereaved during the pandemic experience high levels of grief and emotional support needs, with social isolation/loneliness and death of a close family member particular risk factors. Healthcare professionals' support is associated with better bereavement experiences.

Primary Care

Abstract ID: OA07:01

Abstract type: Oral Abstract

The Cost of Informal Care in the Last Year of Life: A Health Survey for England Study

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Background/aims: People at the end of life need statutory and non-statutory support. Previous cost estimates associated with informal unpaid care by family/friends are based on decedents known to palliative care teams or, if nationally representative, cancer decedents only and only in the last 3 months of life. We aimed to estimate the cost of informal care in the last 12 months of life. People at the end of life need a range of statutory and non-statutory support. Past cost estimates of informal care are based on decedents known to palliative care teams or, if nationally representative, of carers of cancer decedents only and only in the last 3 months of life.

Methods: Population-based survey, England. The Health Omnibus Survey (South Australia) end-of-life caregiver questions were adapted for the Health Survey for England (HSE), 2017. Participants were asked if i) someone close to them had died of a terminal illness < 5 years, ii) they had provided hands-on personal care, and iii) an estimate of the hours of care provided in the last year of life. The unit cost for a community-based homecare worker was applied (\sim £24/hour, 2017). Descriptive statistics are presented.

Results: 521/7997 (6.5%) respondents gave an estimated minimum 403,616 hours (median 186; IQR 26 to 730; range 1 to 8760) and maximum 477,902 hours (288; 52 to 936; 1 to 8760) personal care. Minimum and maximum total costs for personal care provided were £9,668,256 and £11,469,648 respectively. Assuming an English population \geq 16 years of 44,981,459 (2017) this represents national costs for informal personal care in the last year of life of between £0.84 billion and £1.00 billion.

Conclusions: This is a first representative UK population level unit costs estimate of informal personal care in their last year of life. We did not consider lost work opportunities, out of pocket costs, true costs or state benefits received, but does demonstrate the extent to which patients are dependent on the support from family and friends in order to be cared for at home.

Abstract ID: OA07:02

Abstract type: Oral Abstract

Primary Care Provision at the End of Life in Cancer: Care Provision, Continuity and Associations with Hospital Service Usage and Quality Indicators of End of Life Care

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Background/aims: The final six months of a person's life are the most resource intensive in terms of health system usage, with 80% of this expenditure occurring in hospital. Whilst there are considerable data examining hospital service provision, there is little known regarding associated usage of primary care services in the Australian setting.

Objective: This project aims to explore how primary care involvement affects health service usage and quality of life for cancer patients in the last year of life.

Methods: Retrospective cohort study using linked routine care and administrative data from two hospital networks, primary care and national death certificate. Patients were included who were diagnosed with cancer and died from a cause related to cancer between January 2007 - 2017.

Results: A total of 758 patients were included who had linked records from all sources and died from a cancer related cause. General practitioners were closely involved in care during this period, with 88% of patients visiting their GP during the last six-months (mean 9.1 consultations). These visits became more frequent in the last stages of life, with 59% of patients consulting their GP in the last month of life, and 60% the month prior. This care was largely appropriate, with 45% of patients prescribed pain medication, and few requests for imaging (3%) and pathology (9%) in the last month.

Two cohorts were defined on their patterns of GP usage: cohort 1 (n=387) having regular consultations, and cohort 2 (n=371) not having this regularity. The first cohort were older (73.7 vs 67.3yrs, $p < 0.001$) and had more comorbidities (mean 1.1 vs 0.77, $p = 0.002$). Secondary health care usage was alike through both cohorts: admissions in the last three (median 1 [1-2] vs 1 [0-2]) and one (med 1 [0-1] vs 1 [0-1]) month. Rates of indicators of quality end of life care were similar, including palliative care referral (61% vs 59%), and chemotherapy (5% vs 3%), surgery (7% vs 6%) and emergency department use (45% vs 43%) in the last month. Patients in the regular care cohort had longer admissions at 3 months (med 5. [2.8-11.0] vs 4.5 [2.0-9.1] bed days per admission, $p = 0.014$), but this difference was not significant in the last month of life (med 5.7 [2.0-11.0] vs 4.7 [2.0-10.0], $p = 0.312$).

Conclusions: The results demonstrate that these two cohorts have similar patterns of health care usage and indicators of quality end-of-life care. This is despite the first cohort being older and increased comorbid conditions, and thus may have been expected to have more frequent and extended admissions.

Abstract ID: OA07:03

Abstract type: Oral Abstract

Remote Palliative Care Education for Primary Care Occupational Therapists and Physiotherapists: Project ECHO AIIHPC

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Background/aims: Integrated palliative care services are promoted within primary care to address the needs of adults with life-limiting conditions living in the community. Therefore, palliative care education must be delivered to healthcare professionals in the community. Project ECHO (Extension for Community Healthcare Outcomes) uses teleconferencing technology to support and train healthcare professionals remotely. A 4-month fortnightly ECHO programme was developed and implemented to enhance palliative care provision by primary care therapists. Teaching and case-based discussions were facilitated by palliative care specialists.

Methods: A mixed-methods study was used to evaluate the project. ECHO participants completed pre- and post-programme questionnaires regarding their knowledge and skills across key palliative care domains. Focus groups were held with participants before programme commencement to explore their attitudes and experiences of palliative care and after programme conclusion to explore their experiences of the ECHO programme.

Results: 26 primary care therapists commenced the ECHO programme. Self-rated confidence in palliative care knowledge and skills improved significantly ($p < 0.002$) following the ECHO programme. 95% ($n=19$) of participants reported ECHO met their learning needs and 85% of participants ($n=17$) would recommend ECHO to their colleagues. 95% of participants ($n=19$) reported that ECHO was an effective format to enhance clinical knowledge and 75% ($n=16$) reported it was an effective format to in enhance clinical skills.

Conclusions: Project ECHO is an effective and accessible distance learning model which enables primary care healthcare professionals acquire new knowledge and skills within palliative care. In addition to dissemination of best practices, healthcare professionals also benefit from establishing a community of practice. As a low-cost high-impact model, ECHO provides an affordable solution to addressing growing need for integrated palliative care services.

Abstract ID: OA07:04

Abstract type: Oral Abstract

The Effect of Transmural Palliative Care Initiatives on Potentially Inappropriate End-of-Life Care in The Netherlands

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Background/aims: Coordination and continuity of palliative care across different care settings is important to meet the values, wishes and needs of patients and relatives. In the Netherlands, transmural palliative care is rising. Insight into its added value can contribute to further implementation. Our aim was to assess the effect of transmural palliative care initiatives on potentially inappropriate end-of-life care in the Netherlands.

Methods: Using administrative insurance data of all deceased persons in six leading regions between 2016 and 2019, we compared potentially inappropriate care in the last 30 days of life between patients who received transmural palliative care or not. We compared 1) pre and post the start of transmural care initiatives in these regions and 2) adults receiving transmural care with a 1:1 matched control group, matched by age, sex, cancer diagnosis, year of death, and region. Potentially inappropriate care, sum score, was present if one of the following 6 items was found: >1 hospitalization; >14 days hospitalized; >1 admission to emergency department or intensive care unit; in-hospital death; receiving chemotherapy.

Results: Between 2016 and 2019 44,247 people died in the six leading regions. Post-implementation of the transmural palliative care initiatives, less adults received potentially inappropriate end-of-life care (26.5%) compared to pre-implementation (27.9%) ($p < 0.05$). Of the 210 patients who participated in the transmural palliative care initiatives, 50% was female and 69% had cancer. They received less often potentially inappropriate end-of-life care compared to a matched control group, respectively 14.8% vs. 33.8% ($p < 0.05$). This difference was also present for >14 days hospitalization, intensive care unit admission and in-hospital deaths.

Conclusions: Transmural palliative care initiatives seem to have a diminishing effect on potentially inappropriate end-of-life care in patients with life-threatening diseases. Especially the matched control group analysis complements the pre post design study to estimate causal interference. Further development and implementation of transmural palliative care is warranted.

Abstract ID: OA07:05

Abstract type: Oral Abstract

Cost of Quality in Palliative Care Centers: Development of a Questionnaire and its Implementation in a Palliative Care Center

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Background/aims: Cost of Quality (CoQ) is an important tool for ensuring continuous quality improvement, viability and sustainable competitiveness in Organizations which has not yet been tested in Palliative Care (PC). We aim to study and assess the CoQ of PC Centers (PCCs) through the creation of a CoQ evaluation questionnaire specialized in their operating conditions.

Methods: Through a scoping review for CoQ in industry, service companies and healthcare, we identified available CoQ questionnaires only applied in industry. We developed a modified questionnaire to estimate the CoQ both in homecare and inpatient PC services including items where costs incurred either due to low quality or to initiatives taken to achieve high quality. To classify the identified CoQ items the Prevention-Appraisal-Failure Method (PAF) was applied; the items were classified into its 4 categories: prevention, appraisal, internal and external failures. The questionnaire was then validated by a group of experts. Finally, 12 members of the staff of a specific PCC applying a mature Total Quality Management System, used the suggested questionnaire to evaluate its CoQ. Descriptive statistical techniques were applied for the evaluation of data collected by this specific PCC to assess level of impact of each CoQ item and category on its total CoQ and correlation analysis (Pearson correlation coefficient, CCP and P-Value, PV) was used to estimate the correlation between the PAF categories.

Results: A 72 items CoQ questionnaire was developed for PCCs. Its use in a PCC identified an increased level of impact of 3 CoQ items in its total CoQ (mean value >4.5 in a 7-grade scale); the correlation between the 6 couples of the 4 categories of CoQ proved to be high (CCP:0,450-0,850, PV:0,000-0,142) with the prevention cost being predominant.

Conclusions: Our experience showed that the questionnaire can be used as a tool by PCCs to assess their CoQ, identify quality improvement opportunities and develop and implement a Continuous Quality Improvement System.

Non-Malignant Conditions

Abstract ID: OA08:01

Abstract type: Oral Abstract

Triggers for Palliative Care Referral in Burn Intensive Care Units: Results from a Qualitative Interview Study Based on Professionals' Clinical Experience and Knowledge

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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. Burns have significant consequences for patients, families, healthcare teams and systems. Evidence suggests that the integration of palliative care in burn intensive care units improves patients' comfort, decision-making processes, and family care.

Aim: To identify the triggers for palliative care referral in critically burned patients.

Methods: Qualitative study using in-depth interviews. All 5 Burn Intensive Care Units reference centres across Portugal were invited; 3 participated. 15 professionals (12 nurses; 3 physicians) were interviewed from July to October 2020, until reaching theoretical saturation. An inductive thematic analysis was performed to the transcripts of interviews.

Results: The three main triggers for palliative care referral were: (i) Burn severity and extension (e.g., third degree burns and/or +80% of burned body surface); (ii) Co-morbidities (e.g., cancer, organ failures, metabolic failure, dementia, old age +80); and (iii) Multiorgan failure. Other triggers were also identified, namely: (i) rehabilitative palliative care related to patients' suffering and changes in body image; (ii) family suffering and/or dysfunctional and complex family processes; (iii) long stay in the burn intensive care unit; and (iv) uncontrolled pain.

Conclusions: To the best of our knowledge, this is the first empirical study that identifies triggers for palliative care in burn intensive care units based on professionals' clinical experience and knowledge. The systematization and use of triggers tools could help streamline referral pathways and underpin the integration of palliative care in burn intensive care units in a more effective fashion. Further research is needed on the use of these triggers in clinical practice to enhance decision-making processes, early and high-quality integrated palliative care and proportionate patient and family centred care.

Abstract ID: OA08:02

Abstract type: Oral Abstract

Symptom Clusters, Associated Factors and Health-Related Quality of Life in Patients with Chronic Obstructive Pulmonary Disease: A Structural Equation Modelling Analysis

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Aim: To identify symptom clusters and develop a symptom cluster model among people living with chronic obstructive pulmonary disease (COPD).

Background: The examination of symptom clusters in COPD patients is an emerging field of scientific inquiry directed towards more focused symptom management. However, no studies have modelled relationships among symptom clusters, associated factors and health-related quality of life.

Design: A cross-sectional design.

Methods: Data were collected from 450 COPD participants in three Chinese tertiary-level university teaching hospitals between October 2019 and May 2020. Participants were invited to complete a structured questionnaire comprised of a socio-demographic and clinical questionnaire, Integrated Palliative Care Outcome Scale and Clinical Respiratory Questionnaire. Exploratory factor analysis and confirmatory factor analysis were used to identify symptom clusters. Structural equation modelling was used to examine the proposed model.

Results: Three clusters were identified: respiratory related symptom cluster, psychological symptom cluster and cough-insomnia related symptom cluster. The final model demonstrated a good fit with the data ($\chi^2/df=2.982$, CFI =0.970, TLI =0.920, RMSEA =0.066 and SRMR=0.026). Gender, stage of disease and monthly income were significant factors associated with symptom clusters. The respiratory related and cough-insomnia related symptom clusters had a direct negative impact on health-related quality of life, while the psychological symptom cluster was found to have a direct and indirect negative effect on health-related quality of life.

Conclusions: We have developed a COPD symptom cluster model which identifies important structural relationships among symptom clusters, associated factors and resulting health-related quality of life. This model should serve as a framework to guide intervention research targeting symptom clusters to improve health-related quality of life of people living with COPD.

Abstract ID: OA08:03

Abstract type: Oral Abstract

Referral Practices of Respiriologists to Specialist Palliative Care: A Survey Study

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Background/aims: Patients with chronic respiratory disease have specialist palliative care (SPC) needs, but low utilization of SPC services. Poor access to these services may be contributed to by barriers to SPC referral. We sought to determine the referral practices to SPC among respirologists in Canada.

Methods: Respirologists across Canada were invited to participate in an anonymous survey about their referral practices to SPC. Associations between referral practices and demographic, professional, and attitudinal factors were analyzed using regression analyses.

Results: The response rate was 64.7% (438/677). The majority of respondents practiced general respirology (76.7%) and worked in an academic hospital (62.1%). Fifty-nine percent of respondents believed that their patients have negative perceptions of palliative care and 39% were more likely to refer to SPC earlier if it was renamed supportive care. A substantial minority of respondents delayed SPC referral due to uncertainty about prognosis in patients with chronic obstructive pulmonary disease (37.2%) and idiopathic pulmonary fibrosis (24.2%). Only 2.7% never referred to SPC; however, of those that referred, 52.6% did so late in the disease

course. Low frequency of referral was associated with equating palliative care to end-of-life care ($P < 0.001$), not knowing referral criteria of SPC services ($P = 0.015$), and agreement that SPC services prioritize patients with cancer ($P = 0.025$); high referral frequency was associated with satisfaction with SPC services ($P = 0.001$). Late referral was associated with equating palliative care to end-of-life care ($P < 0.001$) and agreement that SPC services prioritize patients with cancer ($P = 0.013$).

Conclusions: Possible barriers to respirologists' timely SPC referral included misperceptions about palliative care, lack of awareness of referral criteria, and the belief that SPC services prioritize patients with cancer. Future studies should confirm these barriers and evaluate the effectiveness of strategies to overcome them.

Abstract ID: OA08:04

Abstract type: Oral Abstract

The Palliative Care Needs of Patients with Multiple Sclerosis, Parkinson's Related Diseases and Motor Neurone Disease: A Secondary Analysis of the OPTCARE Neuro Trial Data

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Background/aims: Long term neurological conditions (LTNCs) are a group of irreversible, degenerative diseases of the nervous system which cause increased disability, cognitive impairment and dependence on others over time. They include Multiple Sclerosis (MS), Parkinson's Related Diseases (PRDs) and Motor Neurone Disease (MND). While specialist palliative care is recommended for patients with LTNCs, only patients with MND are routinely referred at present.

The aim of this research was to describe, compare and contrast the symptom burden and psychological distress of patients with MS, PRDs and MND.

Methods: A cross-sectional secondary analysis of the OPTCARE Neuro trial data was performed. Patients aged 18 or over, severely affected by advanced stages of MS or PRDs or any stage of MND, with an unresolved symptom and one other issue despite usual care were eligible. Demographic data along with disease stage, time since diagnosis, performance status, IPOS Neuro and the Hospital Anxiety and Depression Scale (HADS) were analysed.

Results: Data from 348 participants was analysed - 148 (42.5%) with MS, 177 (50.9%) with PRDs, and 23 (6.6%) with MND. The mean IPOS Neuro-S24 score was highest in the MS group ($M = 27.68$, $SD = 10.3$), followed by PRDs group ($M = 26.86$, $SD = 10.23$) and the MND group ($M = 24.23$, $SD = 10.19$), with no statistical difference found ($p = 0.341$). The most distressing symptoms varied for each diagnosis. The HADS revealed that 26% and 25.2% of participants met the criteria for a diagnosis of anxiety and depression respectively, with no statistical difference between groups.

Conclusions: MS, PRDs and MND patients have a similar burden of distressing physical and psychological symptoms, with some differences in the symptom profiles for each diagnosis. Based on these results, MS and PRDs patients who were eligible for the OPTCARE Neuro trial may benefit from routine referral to specialist palliative care.

Abstract ID: OA08:05

Abstract type: Oral Abstract

Palliative Care for People Who Use Substances During Communicable Disease Epidemics and Pandemics: A Scoping Review

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Background/aims: Communicable disease epidemics and pandemics magnify the health inequities experienced by marginalized populations. Given the pre-existing inequities to palliative care access for people with life-limiting illnesses who use substances, it is important to understand the impact of communicable disease epidemics and pandemics COVID-19 on this population. A scoping review was conducted to answer the research question, "what is known about communicable disease epidemics and pandemics, palliative care and people who use substances?"

Methods: We conducted a scoping review of seven bibliographic databases from the inception of each database to April 2021. We also performed a grey literature search to identify the publications not indexed in the bibliographic databases in August 2020 and June 2021. We extracted quantitative data using a standardized data extraction form and summarized it using descriptive statistics. Additionally, we conducted thematic qualitative analyses and presented our findings as narrative summaries.

Results: Included in our review were 54 records published between 1988 and 2021, of which 18 (33.3%) were peer-reviewed articles. The majority of reported populations were people with advanced HIV ($n = 39$, 72.2%) who use alcohol ($n = 25$, 46.3%) during HIV ($n = 40$, 74.1%) and COVID-19 ($n = 15$, 27.8%) outbreaks. Palliative care outcomes were heterogeneous but fell into four themes: 1) intervention (e.g., symptom management), 2) access (e.g., financial barriers), 3) clinical program (e.g., interdisciplinary collaboration), and 4) policy/guideline (e.g., drug regulations).

Conclusions: Strategies and interventions can be implemented during communicable disease outbreaks to promote equitable access to palliative care by people who use substances.

Geriatrics and Frailty

Abstract ID: OA09:01

Abstract type: Oral Abstract

Provision of Palliative and End-Of-Life Care in Care Homes During the COVID-19 Pandemic: A Mixed Methods Study Designed for Policy Impact

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Background/aims: COVID-19 has had a devastating impact on care homes, their residents and families, and staff. More than 40,000 UK care home residents have died from COVID-19; many more have experienced symptoms and distress. The aim was to explore experiences of care home staff of providing palliative and end-of-life care (PEoLC) during COVID-19, and make policy recommendations.

Methods: Mixed methods study comprising 1) Online survey (in REDCap) of UK care home staff, identified through established networks. The survey was developed from a rapid literature review and included structured and free-text data. 2) Qualitative interviews with care home staff (identified from 1); findings analysed thematically to identify policy recommendations for improving PEoLC.

Results: 107 survey responses from across UK; 57 (53%) had onsite nursing care. 72 (67%) experienced COVID-19 outbreaks; 48 (45%) reported staff shortages; 75 (70%) reported staff stress. Challenges included assessing and managing physical symptoms (17, 16%), spiritual needs (26, 24%) and social/family needs (56, 52%). 26 (24%) reported quality of PEoLC fluctuated during the pandemic.

26 qualitative interviews were carried out. Themes: 1/ Workforce. Staff experienced multiple pressures (more deaths, staff sickness/bereavement, new roles), mitigated by adapting working patterns and living arrangements, providing emotional and practical support, and fostering a sense of partnership. 2/ Integration. Integration with GPs, palliative

care teams, pharmacists and community nurses varied. Digital communications, shared records, hotlines, regular meetings and strong relationships facilitated good PEOLC. 3/ Legacy. Positive outcomes emerged from the rapid changes made, including a sense of empowerment, pride and confidence among staff. This was undermined by feeling under-recognised and undervalued.

Conclusions: Improving PEOLC in care homes is a priority. Recognition of care home expertise, and improved integration with community services, are essential.

Abstract ID: OA09:02

Abstract type: Oral Abstract

"Just Something Human": Older Swiss Nursing Home Residents Discuss their Will to Live

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Background/aims: The will to live (WTL) is an important indicator of subjective well-being. Its understanding may enable better care for older nursing home residents. This study aims to investigate older nursing home residents' definitions and determinants of the WTL.

Methods: Twenty residents (70% women, mean age 85.8 ± 10.3 years), living in four Swiss nursing homes, participated in semi-structured interviews exploring their WTL. Interviews were audio-recorded, transcribed verbatim and thematic analysis was conducted to identify recurrent themes (40% double coded).

Results: Nursing home residents commonly responded that defining their WTL was difficult, with many reflecting on the 'innate' nature of the concept. When asked about the factors that influence their WTL, residents discussed five primary themes:

- 1) relationships, notably with family, friends, other residents, and health professionals;
- 2) their living context in the nursing home, which provides necessary care, constant presence of professionals and security but also implies inconveniences, such as a loss of independence;
- 3) individual factors, such as adaptability and maintaining a positive outlook;
- 4) engagement in routines, including both organized activities and individual daily routines, and
- 5) health status, primarily related to functional health and activities that they are still able to do or that their health status prevents them from continuing.

Conclusions: The importance of relationships, including the impact of the staff's mood and energy levels, via their investment in their work and interactions, on resident's WTL highlights the need to examine and improve the working conditions of staff, not only for their own benefit, but also for the well-being of the residents they care for. Residents' emphasis on their adaptability to various situations should remind health professionals and society to critically reconsider preconceived ideas about the (lack of) WTL of institutionalized older people.

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Abstract type: Oral Abstract

Effect of Home Healthcare on Hospital Admission, Palliative Care, and Mortality for People With Dementia: Evidence from a Nationwide Cohort Study

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Background/aims: Home healthcare (HHC) is crucial for supporting people living with dementia (PLWD) well in the community. Little was known for its longitudinal effect on hospital admission, palliative care (PC), and death in PLWD.

Methods: We conducted a matched cohort study using a nationwide database in Taiwan. The exposure was HHC and outcomes were the subsequent hospitalization, PC, and death. The index date was the date of the first HHC in PLWD with HHC or the same date assigned in matched PLWD. Other covariates included income, urbanization of residency, chronic comorbidities, recent acute illness, specific medication and treatments, previous acute healthcare utilisation. We stratified samples with or without enteral, respiratory, or urinary tubes and performed Cox regression to estimate the adjusted hazard ratio (aHR) and 95% confidence interval (CI) of the risks of outcomes.

Results: Among 305,542 PLWD in 2001-2012, 62,259 PLWD who received HHC and 124,518 matched PLWD without HHC were included and followed to the end of 2013. During the follow-up, 71.1% PLWD had hospitalisation, 1.74% PLWD had PC and 56% PLWD died. The median survival time was 1.2 years after the index date. In PLWD with any kind of tubes, HHC was associated with a higher risk of hospital admission (aHR=1.84, 95% CI 1.40-2.41) but lower risk of mortality (aHR=0.58, 95% CI 0.44-0.76) than those without HHC after adjusting for covariates; whereas HHC was associated with a higher risk of hospital admission (aHR=1.88, 95% CI 1.70-2.09) and mortality (aHR=1.86, 95% CI 1.66-2.08) among PLWD without tubes. In both PLWD with or without tubes, HHC was associated with a lower rate of receiving subsequent PC (aHR=0.91, 95% CI 0.79-1.05, aHR=0.67, 95% CI 0.54-0.82, respectively).

Conclusions: PLWD with HHC are in high need of hospitalisation while HHC may reduce the mortality in PLWD with enteral, respiratory, or urinary tubes. Elements embedded in HHC that enhance the PC use among PLWD should be identified and promoted in future studies.

Abstract ID: OA09:04

Abstract type: Oral Abstract

The Risk of Delirium at the End Of Life: A Retrospective Study in Patients Admitted to Hospice Care

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Background/aims: Identifying risk factors supports early recognition of patients prone to delirium. Although delirium risk score lists are used in hospitals, little is known about their usefulness in patients admitted to inpatient hospice care. This study was performed to examine the predictive value of the 10-item risk screening tool (Risk Score List (RSL), Bannink, 2004 EJPC) in inpatient hospice care facilities, and to examine whether this instrument can be simplified.

Methods: Retrospective medical record study of patients who died in 2019 or 2020 in three hospices. Patient characteristics and the RSL were scored at time of admission. A score ≥ 3 equals a high risk on developing delirium (range 0-16). Predictive values were measured using cox regression analyses and crosstabs.

Results: In total, 240 patients were included. Median age at admission was 78 (IQR 70-84) years, 144 patients (60%) were female, and 186 (78%) had cancer. 173 patients (72%) had an increased risk on delirium according to the RSL, of whom 120 (69%) developed delirium. Total prevalence was 61% (n=147). The RSL significantly predicted future delirium (HR 3.3, CI 1.9-5.7, $p < 0.01$) and had a 85% sensitivity, 43% specificity, 62% positive predictive value and 73% negative predictive value. The RSL was simplified to 4 items (RSL-4; previous delirium, cognitive impairment, opioid switch, age > 70) with three risk categories (low, moderate, high). The RSL-4 significantly predicted future delirium (in moderate risk group HR 2.8 CI 1.6-5.0 and in high risk group HR 5.2 CI 2.9-9.4, both $p < 0.01$). Of patients who were classified as low risk, 28% developed delirium, as moderate risk, 54%, and as high risk, 77%.

Conclusions: Delirium occurs in more than half of patients admitted to hospice care. Determining a high risk at admission helps to identify those more prone to develop this disorder. The RSL-4 showed equal performance and is more easy to use in daily practice than the RSL. Further research is needed to validate this simplified instrument.

Abstract ID: OA09:05

Abstract type: Oral Abstract

Suffering Phenotypes Among Community-Dwelling Persons with Severe Dementia: A Latent Class Analysis

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Background/aims: Persons with severe dementia (PWSDs) experience suffering in multiple dimensions. Determining distinct phenotypes of suffering can guide interventions to reduce suffering. We aimed to delineate distinct suffering phenotypes among PWSDs and to assess their association with PWSD and caregiver characteristics, and one-year mortality among PWSDs.

Methods: We used baseline data from a prospective cohort study of 215 primary informal caregivers of community-dwelling PWSDs. We identified ten indicators representing physical, emotional, and functional suffering and aggressive behaviours, and conducted latent class analysis. We assessed association between delineated suffering phenotypes and PWSD Functional Assessment Staging Test (FAST stage), use of burdensome interventions in past 4 months; caregiver outcomes; and PWSD one-year mortality.

Results: We delineated three suffering phenotypes - Primarily agitated behaviours (phenotype 1; 34%); physical and emotional suffering with agitated behaviours (phenotype 2; 19%); high functional deficits with loss of ability to communicate (phenotype 3; 47%). Phenotype 3 had the highest proportion of PWSDs with most advanced stages of dementia (FAST stages 7B-7F (67%)). Phenotype 2 and 3 PWSDs were more likely to have received a burdensome intervention in past four months and have a greater hazard for one-year mortality. Compared to phenotype 1, caregivers of phenotype 2 PWSDs were more likely to experience adverse caregiver outcomes i.e., higher distress, burden, anticipatory grief, maladaptive coping and lower satisfaction with care received ($p < 0.05$ for all).

Conclusions: The delineated suffering phenotypes will be used to inform holistic dyad-centered interventions to reduce PWSDs' suffering and its potential consequences on their caregivers.

Funding: The study is funded by Health Services Research Grant (HSR-GEoL16Dec002), Ministry of Health, Singapore.

Communication and Advance Care Planning

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Abstract type: Oral Abstract

Time Estimates in MDT Prognostic Discussions: A Conversation Analytic Study of Prognostication within Multidisciplinary Team Meetings from a UK Hospice

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Background/aims: A key feature of prognostication in palliative care is to provide time estimates of patients' survival. However, clinicians' survival estimates are often inaccurate and over-optimistic. Multidisciplinary team (MDT) discussions have been shown to improve prognostic accuracy, but there is a paucity of research on how prognoses are formulated and negotiated between MDT members during these discussions.

This study explored how survival estimates were carried out through conversations in hospice MDT meetings.

Methods: 24 MDT meetings were video recorded from May to December 2021 in a UK hospice. MDT members' consent was obtained either before or after participating in the meeting. Recordings were transcribed and subsequently analysed using conversation analysis.

Results: Prognoses were rarely formulated using "absolute" time estimates such as a certain date, number of days or weeks. Instead, less absolute time references such as '*not having long to go*' were used to display imminent prognoses. The lack of absolute references was most often accepted by other MDT members, not pursuing more absolute and recognitional time estimates. This indicates that a recognitional and shared understanding of non-absolute time references between MDT members is present.

Formulations of time estimates were often produced with pauses in the utterance, cutting off words and restarting sentences. These features display that providing survival estimates is a non-straight forward and potentially problematic interactional activity. This may be due to potential issues with predicting future events, prognostic (un)certainity, and team members being held accountable for their estimates.

Conclusions: Predicting patients' survival is a complex interactional activity even for hospice MDTs. Discussions do not arrive at absolute time estimates, which questions their ability to improve prognostic accuracy *per se*. Other benefits from having prognostic discussions might be present.

Funding: PhD Studentship, Marie Curie Chair (ref: 509537)

Abstract ID: OA10:02

Abstract type: Oral Abstract

"Every Morning, I Offer Her a Cigarette and a Talk" – Results from Health Professionals' Documented Experiences of Desire to Die Conversations with Patients Receiving Palliative Care

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Background/aims: As desire to die (DD) is a relatively frequent phenomenon in patients receiving palliative care (PC), talking openly and respectfully about DD is important for health professionals (HPs). Content and structure of DD-conversations have not been systematically documented yet. Within a multi-phase mixed-methods study, HPs recruited patients for open DD conversations which were documented systematically.

Aims: To analyze HPs documented experiences of DD-conversations with patients receiving PC regarding structure, content, atmosphere and their perceived performance.

Methods: After being trained in dealing with DD, HPs recruited patients for single, open DD-conversations which were reported via documentation sheets with 7 open questions. The qualitative data gathered was analyzed deductively using summarizing content analysis.

Results: From 04/2018-03/2020, 29 HPs documented a DD-conversation with 79 patients. HPs were $M = 46$ years of age, 26 being women and 3 men. Conversations had a mean duration of 43 minutes and in 63 cases (74%) DD was proactively addressed by HPs. A DD was expressed by 19 (23%) of the patients. During data analysis, five main topics emerged: 1) opening questions (e.g., “Do you sometimes have moments in which living feels like a burden?”); 2) patient reactions to them (e.g., “Crying. She felt understood.”); 3) rewarding (e.g., “(. . .) we not only talked about her burden, but were able to tie in with her resource (. . .)”); and 4) demanding aspects (e.g., “Holding up such a conversation is demanding when the patient is not very talkative.”); 5) follow-up measures (e.g., “I explained the legal situation (. . .) – for me, it was the first time (. . .)”).

Conclusions: HPs addressed DD in a variety of ways which was largely received positive by their patients. Despite reporting some patients’ hesitation to engage in the topic, HPs used DD-conversations to address wishes, fears and future care planning.

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Complexity of Implementing a Nationwide Advance Care Planning Program: Results from a Qualitative Evaluation

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Background/aims: Singapore implemented a national advance care planning (ACP) program in 2011 within acute care settings. The program was expanded to primary care settings and nursing homes in 2017. We conducted a qualitative evaluation of the second phase of the national ACP program to understand the organizational and operational barriers to integrating ACP in routine clinical care.

Methods: We conducted focus group discussions (FGDs) with a purposive sample of healthcare professionals (HCPs) within acute care hospitals, primary care clinics and nursing homes. FGDs were stratified into three categories based on role of HCPs within the ACP framework - leaders *versus* facilitators and advocates *versus* nursing home heads. Data was thematically analysed and emergent themes mapped to the Conceptual Framework of Implementation Research (CFIR).

Results: Overall, 23 FGDs included 107 participants from 25 organizations. Findings revealed wide variation in ACP implementation among organizations, and identified 13 themes organized within four CFIR categories – outer setting (lack of public awareness, shortcomings in inter-organizational partnerships, performance driven policies), inner setting (lack of commitment from organizational leadership, paucity of dedicated resources, absence of an institution-wide ACP culture, lack of physician engagement within the ACP process, lack of capacity to support patient preferences), characteristics of HCPs (language as a barrier) and process (inadequate training framework, complexity of conversations and documentations,

challenges to retrieving ACP documents, absence of comprehensive monitoring and evaluation).

Conclusions: We found that in order to integrate ACP within routine clinical care, ACP processes should be simplified, training framework be strengthened, physicians be engaged and an ACP supportive culture be created within and outside organizations. Findings will guide the next phase of program implementation.

Abstract ID: OA10:04

Abstract type: Oral Abstract

Inclinations to Strive for Quality and Length of Life among Patients with Advanced Cancer and a Poor Prognosis

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Background/aims: When discussing palliative chemotherapy, advanced cancer patients need to consider quality and length of life (QoL/LoL). To assure care matching patients’ wishes, insight into their attitudes towards striving for QoL/LoL is vital. Our aim was to study the distribution and development of attitudes towards striving for QoL/LoL among advanced cancer patients, and predictors of these attitudes (over time).

Methods: Secondary multilevel analysis of an RCT on shared decision-making (SDM) about palliative chemotherapy, using recorded consultations and surveys at baseline (T0), shortly after the consultation (T2), at 3 and 6 months (T3, T4). We included 173 patients (all RCT conditions; 51% male, $M_{age}=63.5$) with metastatic cancer, median survival of <12 months without anticancer therapy and median survival benefit of <6 months from palliative chemotherapy, reporting attitudes towards striving for QoL/LoL at least once (T2/T3/T4).

Results: Results are preliminary. Distributions of patients being more inclined to strive for QoL than LoL, more inclined to strive for LoL than QoL, and valuing QoL and LoL evenly, were equal at T2, T3 and T4. About 40% of patients changed these preferences in either direction; 24-34% altered inclinations for QoL/LoL over time ($SD \geq 0.8$). At group-level, inclinations for QoL declined (T2-T4, $p=.007$), yet were stable for LoL. Helplessness/hopelessness ($p<.001$) and SDM ($p=.015$) related positively, while fighting spirit ($p=.028$) and anxiety ($p<.001$) related negatively to attitudes towards striving for QoL. Fighting spirit and anxiety related positively, while helplessness/hopelessness and education related negatively to attitudes towards striving for LoL (all $p<.001$).

Conclusions: Observed changes in patients’ inclinations for QoL/LoL over time appear to call for repetitive discussions of patients’ attitudes towards the aims of treatment. Our results also seem to underline the relevance of exploring of patients’ personal characteristics during SDM.

Funding: Dutch Cancer Society.

Abstract ID: OA10:05

Abstract type: Oral Abstract

Advance Care Plans: Creation, Content and Use During Wave 1 of the COVID-19 Pandemic. A Retrospective Cohort Study of Coordinate My Care, a Large Electronic Palliative Care Coordination System

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Background/aims: Mortality forecasts associated with COVID-19 pandemic stressed a need to prepare adults with advanced disease for possible severe illness and engage with Advance Care Planning (ACP). We aimed to examine ACP engagement and activity during the COVID-19 pandemic.

Methods: A retrospective non-interventional cohort study, comparing the creation, content and use of Coordinate My Care (CMC) records that include an ACP component, in London, prior to and during the onset of COVID-19. Records for people aged 18+, created and published in pre-pandemic period (2018-2019) and 'wave 1' (W1) of COVID-19 (20/03/20-04/07/20) were extracted. Demographics, ACP-related content and the use of CMC records created were analysed and compared using standard descriptive statistics.

Results: 56,343 records were included, 35,108 from the pre-pandemic period and 21,235 records from W1. The average records created each week rose by 296.9% ($P < 0.005$) in W1. There were fewer records in W1 for those aged 80 years (60.8% vs 64.9% pre-pandemic, $P < 0.005$) and who had WHO performance status of 4 (34.8% vs 44.2% pre-pandemic, $P < 0.005$). More people who created records during W1 had an estimated prognosis of at least a year (73.3% vs 53.0% pre-pandemic, $P < 0.005$), were "For Resuscitation" (38.2% vs 29.8% pre-pandemic, $P < 0.005$) and had a Ceiling of Treatment of "Full Active Treatment" (32.4% vs 25.7%, $P < 0.005$). More people in W1 listed hospital as their preferred place of care (PPC) and preferred place of death (PPD) (PPC: 13.3% vs 5.8% pre-pandemic, $P < 0.005$. PPD: 14.0% vs 7.9%, $P < 0.005$). Average monthly non-urgent and urgent record views rose by 320.3% ($P = 0.02$) and 154.3% ($P = 0.01$) in W1.

Conclusions: A large uptake in engagement with ACP is demonstrated during the 1st wave of the pandemic. An increase in use among younger, more independent patients with longer prognoses, with a higher preference for hospital care creating records in W1 compared to before the pandemic, suggests heightened awareness and provision of ACP at this time.

Paediatric Palliative Care: Quality, Measurement and Relationships

Abstract ID: OA11:01

Abstract type: Oral Abstract

Comprehensibility, Comprehensiveness and Acceptability of a Novel Paediatric Palliative Care Outcome Measure: A Cognitive Interview Study with Children and Families

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Background/aims: A systematic review found no validated outcome measures suitable for use with children and young people (CYP) with life-limiting/life-threatening conditions in developed countries. A measure was developed following a qualitative semi-structured interview

study and a Delphi survey with key stakeholders. This study aims to cognitively test this novel child and family-centred outcome measure to assess and improve comprehensiveness, comprehensibility and acceptability in the UK.

Methods: The 13-item C-POS for CYP 0-17 years old and their parent/carer was cognitively tested face to face or virtually using 'think aloud' methodology, and verbal probing. Audio recordings were thematically analysed using Tourangeau's cognitive processing model – understanding, recall, judgement and response.

Results: 12 interviews were conducted in three waves from 6 UK sites. Refinements made included: re-wording items to increase acceptability for non-verbal CYP (from 'share' to 'express' feelings; from 'being able' to ask questions to 'having the right amount of information'); and changes to improve comprehensibility (a question designed to ask about advance care planning was not interpreted as intended so was reworded). Measure content and length were acceptable, and all questions were reported to be important. Although the advance care planning question was distressing for some parents, they felt it should be included. The 5-point Likert scale response format and recall period of 1-week (for parents and older children) and yesterday or today (for younger children) were well understood. There were no suggestions for additional items, suggesting good face and content validity.

Conclusions: Cognitive interviewing helped to refine the prototype C-POS, especially to be inclusive of CYP who were non-verbal. This study has enhanced the face and content validity of our measure and provided some preliminary evidence for acceptability for use in routine practice.

Funding: Funded by the European Research Council [Grant ID: 772635].

Abstract ID: OA11:02

Abstract type: Oral Abstract

Quality of End-of-Life Care in Children With Neurological Conditions in Belgium: A Population-Level Evaluation Using Face-Validated Quality Indicators

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Background/aims: Neurological conditions, such as cerebral palsy and muscular dystrophy, are the main diagnoses of referral for many paediatric palliative care teams. Nevertheless, parents of children with such conditions globally report insufficient end-of-life care. Population-level measurement of end-of-life care appropriateness provides a quality-of-care overview that is currently lacking, and offers options for care improvement. Therefore, the aim of this study was to evaluate the quality of end-of-life care in children who died with neurological conditions using face-validated quality indicators.

Methods: Retrospective observational study on the full population of 159 children between the ages of 1 and 18, who died with neurological conditions, between 2010 and 2017, with healthcare claims data in Belgium. We measured 24 quality indicators, 13 for potentially appropriate and 11 for inappropriate care.

Results: For indicators of potentially appropriate end-of-life care, 65% of children received multidisciplinary care and 48% of children had contact with a general physician in the last month before death. 13% of children received a palliative status, i.e., a stipend for palliative care. No children received follow-up consultations at the hospital after palliative status. For potential inappropriateness of care, 16% of children were admitted to an Intensive Care Unit 2 weeks before death. 36% of children received blood tests or CT/MRI/X-ray monitoring in the last 2 days before death, 2% of children underwent surgery 2 days before death.

Conclusions: Multidisciplinary care was frequent, yet only a minority of children received palliative stipends, general physician contact or hospital follow-up, suggesting a need for provider contact and administrative

support. Inappropriate care was potentially low, yet blood tests and monitoring prevalent, which could stem from overtreatment, symptom control, or patient or family wishes. Further studies best research patient perspectives.

Funded by Research Foundation Flanders

Abstract ID: OA11:03

Abstract type: Oral Abstract

How Can We Measure Quality of Dying, Death, and Quality of Care at the End-of-Life for Children and Young Adults? A Scoping Literature Review

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Background/aims: The death of a child or young adult is fundamentally painful. Evaluating end-of-life care experiences can identify specific needs and ensure good quality care is provided.

Our aim was to identify tools assessing quality of dying, death or end-of-life care for children and young adults.

Methods: Scoping literature review following methodological framework of Arksey and O'Malley. Four electronic databases (MEDLINE, CINAHL, EMBASE and PsychInfo) searched (January 2000–January 2021). Reference lists and citations also screened. Each identified tool assessed for content, context of use and psychometric properties.

Results: From 1663 papers, 19 studies were included in the review, reporting on 11 tools used in 7 different countries. Most tools (n=6) were used within a cancer setting; 4 within the context of both malignant and non-malignant disease; 1 used solely with advanced cardiac disease. All tools had been used with the primary caregiver (n=7; majority were mothers 56% - 93.6%), with healthcare professionals (n=3) or both groups (n=1). No tool had been used with siblings. Items assessing pain/symptom control and quality of communication were found in all tools; only four addressed aspects of religious/spiritual care. For tools used within the cancer setting, 4 had specific psychometric testing (Good Death Inventory-Paediatrics; Paediatric Intensive Care Unit – Quality of Dying and Death; Quality of Children's Palliative Care Instrument and Measure of Quality of Life at End of Life of paediatric cancer patients). For tools used with both malignant/non-malignant disease, 3 had tested psychometric properties (PELICAN Questionnaire, Quality of Children's End-of-Life Care Instrument and Paediatric Intensive Care Unit – Quality of Dying and Death).

Conclusions: Future focus may be best placed on further refining and validating existing tools. Whether tools such as these are suitable for assessing experiences of siblings needs further exploration.

Abstract ID: OA11:04

Abstract type: Oral Abstract

Does It Get Better with Age? Exploring the Relationship Between Canadian Cardiologists and Respirologists with Specialized Palliative Care

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Background/aims: Children and adults with advanced cardiac and respiratory disease may benefit from specialized palliative care (SPC). However, there is limited data summarizing the delivery of SPC in this population and how it may differ between pediatric and adult contexts. This study sought to explore pediatric cardiologists and respirologists (CRs) beliefs about and referral practices to SPC and compare these results to adult CRs.

Methods: CRs listed in the Canadian Physicians' Directory were sent a survey exploring SPC referral practices and beliefs. Responses were summarized with descriptive statistics. Pediatric and adult CRs' responses were compared using Pearson's chi-square test.

Results: Response rate was 56.2% (989/1759). 8.8% (87/989) were pediatric CRs. Pediatric CRs were more likely to be younger ($p=0.003$), female ($p<0.001$), work in an academic centre ($p<0.001$), and experience fewer patient deaths ($p<0.001$). Across ages, the perceived availability of inpatient SPC was higher than that of hospice or home care. Pediatric CRs reported better access to inpatient SPC and bereavement care ($p<0.001$). Adult CRs reported better access to palliative care units ($p<0.001$). Pediatric CRs referred to SPC earlier, while adult CRs were more likely to refer after active treatments were stopped ($p<0.001$). More than half of all CRs felt patients negatively perceived palliative care. Most pediatric and adult CRs were satisfied with SPC quality (81.6 and 72.7%); however, fewer adult CRs were satisfied with SPC availability (74.4 vs. 47.3%; $p<0.001$). Fewer pediatric CRs felt that SPC prioritized oncology patients (12.6 vs. 53.0%; $p<0.001$).

Conclusions: There are important similarities and differences between pediatric and adult CRs' beliefs about and referral practices to SPC. This may reflect unique features of pediatric diseases (e.g., prognosis), provider traits, care philosophies, or service availability. Understanding these differences provides an opportunity for pediatric and adult CRs to learn from each other.

Paediatric Palliative Care: Experiences, Communication and Compassion

Abstract ID: OA12:01

Abstract type: Oral Abstract

Parents' Experiences of Being Involved in Medical Decision Making for Their Child With a Life-Limiting Condition: A Narrative Review

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Background/aims: Parental involvement in the decision-making processes about medical treatment for their child with a life-limiting condition is recognised as good practice. Previous research has highlighted factors affecting the decision-making process, but little is known about how parents experience their participation.

Methods: A systematic narrative review following the PRISMA guidelines. Medline, EMBASE, SCOPUS, CINAHL and PsycINFO were searched in December 2020. Quality assessment was included.

Results: From the initial 1652 citations identified; 21 papers met the inclusion criteria, the majority of which used qualitative design. The types of medical decisions varied but stopping general or life-sustaining treatment was the most frequent. A narrative synthesis revealed four themes:

- (1) Losing control of the situation: parents had difficulties comprehending the situation and foreseeing the outcomes of their decisions;

- (2) Transferring the power to decide to the doctor: parents intentionally handover the responsibility to doctors due to a lack of medical knowledge and confidence;
- (3) Finding a balance - being a parent while protecting the child: balancing the best interests of the child and their own wishes while making the decisions;
- (4) Identifying sources of support to alleviate the parental experience: support strategies used by parents, including compassionate and truthful input from health care professionals, support from family and friends or faith.

Conclusions: Parental experiences with decision-making are complex and multifactorial but participation in the process is limited by a lack of empowerment and the challenging circumstances in which decisions take place. Health care professionals need to support parental involvement in an effective way, instead of just formally asking them to participate. More research is needed on exploring how to enhance parental role in decision-making.

Abstract ID: OA12:02

Abstract type: Oral Abstract

Insight Into the Content of and Experiences With Follow-up Conversations in Pediatrics: A Systematic Review

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Background/aims: During their child's end-of-life (EOL), parents are suppressing grief to endure the situation and be present with their child. This increases the need for bereavement care after the child's death to support parents in their grief. Follow-up conversations are a well-established form of bereavement care in pediatric clinical practice, yet an understanding of the content and value of these conversations is still lacking. The aim of this study is to provide insight into the content of- and experiences with follow-up conversations in pediatrics, from the parents' and the HCPs' perspective.

Methods: Systematic literature review using the methods PALETTE and PRISMA. The search was conducted in PubMed and CINAHL on February 3, 2021. The results were extracted and integrated using thematic analysis.

Results: Ten articles were included. Follow-up conversations are built around three key elements. (1) Gaining information: parents receive a full picture on all proceedings during their child's EOL and receive answers to lingering questions. (2) Receiving emotional support: parents want to feel that HCPs cared about them and their child and parents require reassurance that everything possible had been done. (3) Facilitating parents to provide feedback: parents may provide HCPs with feedback on care that needs improvement and express their gratitude for the good care received. The vast majority of parents and HCPs experienced follow-up conversations as meaningful and beneficial for several reasons, including finding closure.

Conclusions: This review provides practical tools on the content of follow-up conversations and how to tailor these conversations to the bereaved parents' needs. Parents found follow-up conversations meaningful and helpful in their grieving process, yet further research is required to assess parents' needs regarding reassurance versus working towards honest reflection on the child's treatment and care.

Abstract ID: OA12:03

Abstract type: Oral Abstract

Children's and Young People's Participation in Consultations with Paediatric Oncologists: An Analysis of On The Ground Interactions

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Background/aims: Children's and young people's (CYP) participation in clinical consultations has been endorsed as an important aspect of their care and treatment. However, there is no consensus in the literature as to what CYP's participation involves or what form it takes. Several recent studies based on interviews with CYP have questioned previous understandings of participation in consultations and have proposed changes in how CYP's participation is understood. This presentation explores CYP's participation in paediatric oncology consultations.

Methods: Taking an interactionist perspective, analysis was conducted on verbatim transcripts of audio-recorded consultations from a wider study of CYP with high-risk brain tumours. The CYP's participation in the consultation was explored as a triadic process. Data analysis employed constant comparison and tools from discourse and conversation analysis.

Results: CYP were embedded in the conversation by the design of the clinician's speech, which irrespective of the CYP's responses, was often directed to the child or young person. CYP took turns in the consultation without adult resistance. CYP's views were sometimes co-produced in the consultation by working together with parents.

Conclusions: Conversations in consultations were predominantly triadic. Understanding the CYP's participation requires an approach geared to deal with such a context. Measures such as participant's total time speaking fail to reflect the role a participant plays or the impact they may have on a consultation. Further research in this direction is needed to better understand CYP's participation in clinical consultations and to hear the voices of CYP.

Abstract ID: OA12:04

Abstract type: Oral Abstract

How Is Compassion Understood and Experienced by Pediatric Advanced Cancer Patients, Parents, and Their Healthcare Providers: A Grounded Theory Study

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Background/aims: Compassion is considered a standard of pediatric palliative care yet little empirical research has been conducted investigating the nature, evidence, and impact of compassion from the perspectives of those at the bedside—pediatric patients, parents, and healthcare providers. This is the first known study that focused on the topic of compassion specifically within pediatric palliative care.

Methods: After conducting a large scoping review, 33 pediatric patients living with advanced cancer, 16 parents, and 17 healthcare providers were recruited from 4 Canadian academic pediatric hospitals via both face-to-face interviews and online (Skype) interviews. Data was collected and analyzed in accordance with Straussian Grounded Theory, with each member of the research team individually analyzing each interview transcript in a line-by-line fashion. Individual codes within each transcript were then compared amongst team members in team meetings until consensus was reached, producing a coding schema which guided future analysis.

Results: Categories and associated themes generated from interview data produced the Pediatric Compassion Model, delineating the key components, flow, and nature of compassion. The four domains/key components

of compassion were beneficence; human relating; seeking to understand; and attending to needs, which together constituted compassion. While there was general agreement across participant groups and developmental stages, patients and parents were more likely to emphasize the beneficial qualities of healthcare providers in describing compassion, whereas healthcare providers emphasized behaviours embedded within the categories of seeking to understand and attending to needs.

Conclusions: The Pediatric Compassion Model provides researchers and clinicians with an evidence informed foundation to advance compassion in pediatric palliative care practice and research. Future compassion research in pediatric palliative care should focus on measure development and training interventions.

Poster Abstracts

Care Setting

Abstract ID: P01:01

Abstract type: Poster

Rapid Response Service Models in End of Life Care: A Realist Evaluation

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Background/aims: Research has identified a lack of out-of-hours and community services to support people at the end of their lives. Rapid Response Services (RRS), facilitate the patient's choice to die at home; aiming to cut the risk of unplanned hospital admissions and minimise delayed discharges. Yet, there is little evidence about how RRS enhance end-of-life experiences and outcomes or their economic impact. This presentation draws on an on-going realist economic evaluation of two RRS in England. It will present a novel, transparent approach used to develop Initial Programme Theories (IPTs), their early revision, the integration of mid-range theories (MRTs), into the first stages of testing.

Methods: Realist evaluation is a theory-driven approach which seeks to understand what it is about an intervention that works, for who, in what circumstances, and why. This 2-year project has 3 phases: P1 includes IPT development, scoping activity, focus groups, and interviews with staff who work in, and with, the RRS (n=42); P2 will include interviews with carers (pre/post bereavement) and patients (n=38); and P3, undertaken concurrently, will investigate resource use.

Results: Eight significant areas of inquiry were identified: Communication; Values; Access; Diverse Needs; Geography; 12 v 24 hr; Timeliness; Who. For each area, IPTs were generated through literature scoping, interrogation of secondary sources, stakeholder information gathering, and the application of MRTs (Normalisation Process Theory and Transitions Theory). Each IPT explicitly recognises relevant contexts, mechanisms and outcomes (CMO configurations). These IPTs fed into the development of focus group and interview schedules for data collection.

Conclusions: A novel method for the development of IPTs for a realist evaluation of EoLC (RRS) has been developed. This process identifies multiple inquiry areas, that were subsequently revised through scoping and prepared for testing through empirical research.

Funding: Research is grant funded from Marie Curie

Abstract ID: P01:02

Abstract type: Poster

A Delphi Study to Understand the Most Important Components of Out-Of-Hours Community Care For Patients Approaching the End of Life and Their Family Carers

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Background/aims: The proportion of home deaths has increased during the COVID-19 pandemic. Most patients prefer to die at home. However, >75% of time falls outside of normal working hours (out-of-hours), and community services for palliative patients out-of-hours are variable and the best evidence-based models of care have not been determined. This study aimed to establish expert consensus on the most important components of out-of-hours community palliative care services.

Methods: A two round Delphi study was conducted following the CREDES guidance (Guidance on Conducting and REporting DELphi Studies in palliative care). The first round listed 68 components generated from systematic literature reviewing, focus groups with healthcare professionals, and patient and public involvement (PPI) consultation. Components deemed 'essential' by over 70% of respondents were refined and carried forward to a second round, where participants were asked to rank each component on a five-point Likert scale. The threshold for consensus was median 5, interquartile range ≤ 1 . Participants were community specialist palliative care health professionals, district nurses and general practitioners, patients, and family carers with experience of providing/receiving care out-of-hours at home.

Results: 54 participants completed round 1; 46 components met consensus. 44 participants completed round 2; 45 refined components met consensus including: prescription, delivery and administration of medicines; district and community nurse visits; shared electronic patient records and advance care plans, all reaching highest consensus. There was little disagreement between healthcare professionals and PPI although home visits from out-of-hours general practitioners did not reach consensus among PPI but did among healthcare professionals.

Conclusions: These findings provide valuable evidence for service provision, future service design, and research in evaluating models of care.

Funding: Marie Curie research grant

Abstract ID: P01:03

Abstract type: Poster

Advance Care Planning Conversations in Primary Health Care Helps Cancer Patients to Spend More Time at Home and to Die at Home: A Mortality Follow-Back Study

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Background/aims: Spending time at home and dying at home is advocated to be a desirable outcome of palliative care (PC). In Norway, home deaths among cancer patients are rare compared with other European countries. Advanced care planning (ACP) conversations enable individuals to define goals, preferences for future medical treatment and care and to record and review these with a palliative plan if appropriate. ACP

in primary health care, reflecting a person's wishes and current medical condition, supports treatment at home for all present and possible future health care providers.

Methods: The study included 250 cancer patients in the Romsdal region with or without an ACP conversation in primary health care that died in the two years period September 2018 to August 2020. The patients were identified through their contact with the local hospital, cancer outpatient clinic or hospital-based palliative care team.

Results: During the last 90 days of life, patients who had an ACP conversation in primary health care (N=125) were mean 9.8 more days at home ($p = 0.001$), 4.5 less days in nursing home ($p = 0.14$) and 5.3 less days in hospital ($p = 0.002$). After an ACP conversation in primary health care, patients were significantly more likely to die at home ($p < 0.001$) with a four times higher probability (RR=4.4). Likewise, the probability of dying in hospital was approximately three times lower (RR=0.32). Contact with the hospital-based PC team did not affect days at home or death at home significantly, but patients were more likely to have an ACP conversation in primary health care.

Conclusions: Palliative cancer patients with an ACP conversation in primary health care spent significantly more days at home and more frequently died at home. A joint responsibility between GPs, community cancer nurses and home care nurses with initial support from hospital-based PC team is an important collaboration strategy of primary and specialist health care to help cancer patients to stay at home and to die at home.

Abstract ID: P01:04

Abstract type: Poster

Building CAPACITI for Palliative Care in Primary Care: Early Results From a Randomized Controlled Trial of an Educational Intervention in Canada

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Background/aims: Primary care providers play an important role in providing early palliative care (PC), however they lack practical supports to help them operationalize this approach in practice. CAPACITI is a virtual training program aimed at providing practical tips, strategies, and action plans to provide early PC approach. The entire program consists of 12 sessions (1 hour each), divided evenly across three modules: (1) Identify and Assess; (2) Enhance Communication Skills; (3) Enhance Skills for Ongoing Care. We will provide an overview of this program and early findings from our trial.

Methods: A randomized controlled trial to evaluate two modes of CAPACITI program delivery: 1) self-directed learning, where participants access materials online; and 2) facilitated learning, where participants are also invited to live webinars to discuss the online materials. The primary outcomes are percent of patients identified for PC and timing of first initiation of PC. Secondary outcomes include self-reported competency, patient-centered communication, and effective care delivery (EPCS tool), and team collaboration (AITC-II tool), as well as qualitative interviews. Covariates of interest are readiness for change (ORCA tool), team size, and learning preference. We are recruiting 4 cohorts between October 2021 and March 2023.

Results: To date, the first cohort included 73 primary care teams from across Canada, representing 210 providers. About a third of these teams had 4 or more members that participated in the CAPACITI Module; overall, representing registered nurses (33% of participants), nurse practitioners (17%), social workers (12%), physicians (9%), and clinical

coordinators/managers (14%). We will report the results of our outcomes from cohort 1 for Module 1 at the conference, including qualitative analysis.

Conclusions: CAPACITI is a national trial aimed at behavior change in primary care providers. Learnings from the trial will inform future palliative care educational initiatives.

Abstract ID: P01:05

Abstract type: Poster

Interaction of General Practitioners and Members of Specialized Outpatient Palliative Care Teams in the Kopal Case Conferences on Patients With Advanced Chronic Diseases: A Qualitative Study

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Background/aims: In Germany, up to 90% of patients with congestive heart failure, COPD, or dementia are primarily treated by general practitioners (GPs). Early coordinated care provision is thought to improve symptom control (e.g., pain, respiratory distress, fear), stabilize quality of life, and reduce the number of hospitalizations. This study is part of the project "Strengthening interprofessional collaboration for patients with non-oncological palliative care needs – development and evaluation of a new concept: the multicenter KOPAL randomized controlled trial" (KOPAL). This study examines the interprofessional interaction of GPs and members of specialized palliative home care (SPHC) teams in case conferences (CCs) on patients with chronic advanced diseases after a comprehensive nursing assessment in their home environment, based on the KOPAL conversation guide.

Methods: Between January 2020 and March 2021, 78 CCs were conducted on the phone. Non-participating observers documented details of each CC using an observation protocol (e.g., performance of counselling, interpersonal constellation). The written protocols were analyzed using Kuckartz structuring content analysis methodology and MAXQDA 12.

Results: CCs were mainly characterized by a cooperative and welcoming atmosphere and objective discussions, often led by SPHC-nurses. GPs often showed great interest in the findings of the nurses and their manifold suggestions for improvement of patient care. SPHC-doctors mainly addressed medication regimens and emergency preparation. Single communication barriers were observed.

Conclusions: CCs helped to identify gaps in care provision and strategies to address them. It remains unclear to which extent results were considered for follow-up care by GPs or will improve future interprofessional collaboration.

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Abstract ID: P01:06

Abstract type: Poster

How to Integrate Palliative Care Within Primary Healthcare- Perspectives of Patients With Serious Illnesses, Their Family Caregivers and Primary Healthcare Professionals in Nigeria

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Background/aims: Palliative care should be integrated into primary healthcare systems within low- and middle-income countries to help achieve Universal Health Coverage. We aimed to identify preferences and expectations for support among people living with serious illness and their families, and implications for palliative care integration among healthcare providers at the primary healthcare level in Nigeria.

Methods: Using a semi-structured self-designed interview guide, we interviewed people with serious illness (n=21), their family caregivers (n=15) and healthcare providers (n=12) from three primary healthcare facilities in Nigeria between January and March 2020. Interviews were transcribed and transcripts were analysed using thematic analysis.

Results: Three major themes were identified. 1) Engaging patients requires existing trust and bonds from their current use of primary healthcare and support to develop patient agency. 2) Balancing patients and families' expectations and preferences for easily accessible service with adequate staffing and opportunities for social interaction and adequate communication. 3) Addressing staffing related issues to ensure an appropriate response to patients with serious illnesses, inter-professional trust and clear role delineation.

Conclusions: Expanding palliative care integration within primary healthcare in Nigeria can be achieved through building information and communication skills of healthcare providers, engaging and empowering patients to exercise their agency in care decisions, and adequately delineating healthcare providers' roles to ensure staff work within the limits of their competencies and training.

Abstract ID: P01:07

Abstract type: Poster

A Theory of Change for an Integrated Primary Palliative Care Intervention for Patients With Serious Illnesses in Nigeria

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Background/aims: About 80% of people living with serious health related suffering in low and middle-income countries lack access to palliative care, in part due to inadequate integration of palliative care into health systems. We developed a feasible logic model and causal pathway of the integrated primary palliative care intervention for persons with serious illnesses and their families.

Methods: 18 nurses and 1 doctor from primary healthcare centers and 9 palliative care specialists (5 doctors and 4 nurses) from a tertiary hospital in Nigeria participated in two theory of change workshops conducted online. Patients vignettes and research results on expectations of patients were presented. Breakout rooms were used for small group discussions and mindmaps.app was used to collate and map ideas in real-time.

Results: The causal pathway highlights: prerequisites for integration i.e., availability of specialist palliative care team and willing non-governmental organisations for referrals of complex needs, medicines access and social support needs; implementation consideration i.e., engaging patients, families and communities through street-to-street awareness and ward health committee meetings, provision of information, education and communication materials about serious illnesses, and palliative care training and supervision for primary healthcare providers;

Outcomes i.e., improved knowledge of serious illnesses, feeling heard and valued, physical and psychological symptom relief, reduced financial and caring burden.

This model is based on assumptions that patients and family members understand the usefulness and relevance of the intervention and primary healthcare providers adapt the intervention into their ways of working.

Conclusions: Theory of change workshops can be conducted successfully online. The developed integrated primary palliative care intervention logic model highlights the causal pathways to achieve the desired outcomes of the intervention. The model requires feasibility and effectiveness testing.

Abstract ID: P01:08

Abstract type: Poster

Impact of COVID-19 Lockdown on Chronic Lung Disease Patient Experiences of Primary Health Care Services in Cape Town, South Africa

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Background/aims: Chronic Obstruction Pulmonary Disease (COPD) is currently the third leading cause of death globally. COPD and chronic lung disease patients experience multidimensional symptoms throughout the disease course. Research shows palliative care alongside usual care for people living with COPD can reduce breathlessness and improve quality of life. Access to palliative care for these patients is limited, particularly in LMICs. In addition, the COVID-19 lockdown resulted in restrictions on chronic care delivery at primary care facilities.

Aims: To describe the impact of the COVID-19 lockdown on patient experiences of primary care.

Methods: The data reported is from a cohort of 49 chronic lung disease patients recruited for a feasibility stepped wedge hybrid type II design RCT trial of integrated person-centred palliative care in primary care in Cape Town, South Africa. Data are open-text responses to a single question on a validated measure of primary care consultation empathy (CARE). These describe patient experiences of the impact of the lockdown on the primary care received, prior to crossover to trial intervention.

Results: Thirty two patients responded to the question at least once between March and December 2020. Seventeen participants were female (53.1%) and the mean age was 58.6 years. Inductive analysis of the open-text data identified four main themes. Despite home delivery of chronic medication, participants described decreased access to chronic care and a desire for more person-centred care. The socio-economic ramifications of the lockdown added to the burden experienced.

Conclusions: The COVID-19 lockdown primary health care service restrictions caused a disruption to the continuity of care for patients, with associated worry, anxiety and disappointment. There are opportunities for providing more sustained person-centred care through referrals to community health workers and through telephonic patient support.

Funding: NIHR and UK Aid

Abstract ID: P01:09

Abstract type: Poster

Implementing a Transmural Palliative Care Protocol in a Homecare Region: A Mixed Methods Study Including Costs and Effects

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Background/aims: Palliative care is increasingly delivered at home. However, 24/7 access to palliative care expertise at home varies. Therefore, a palliative care program was implemented in a large home-care region, including education of homecare nurses (coaches) and a regional palliative care protocol including demarcation of palliative patients, integrated care planning between patients/families/ (specialized) nurses/GP, and support of a hospital palliative care team. Aims of the study were (1) to evaluate the percentage of patients dying at home, and (2) to investigate healthcare utilization and costs during the last 3 months of life.

Methods: A pre-post study design was implemented. Patient inclusion for the care protocol ran from September 2019 until March 2020, with follow up until June. Data of patients receiving the integrated care protocol were compared to other regionally deceased patients that received homecare at some point in the last 6 months of life (cohort 2017-june 2020), using regional insurance data. Statistical analyses included regression models and interrupted time series. A process analysis with caregivers and relatives is performed (but not reported here).

Results: In total, 3,411 patients were included in the dataset (2603 before start of the intervention, 808 afterwards). Of these, 126 received the palliative care protocol. A significant increase of home deaths was reported for the protocol patients (OR=2.16, $p<.01$) with a significant decrease in hospital deaths (OR=0.53, $p<.05$). For protocol patients, the risk rates for hospital admission (IRR 0.65, $p<.01$) and for emergency department visits (0.76, $p<.05$) were significantly lower. The care protocol resulted in average monthly saving of 310 euro per regional patient ($p<.01$).

Conclusions: The introduction of a regionally integrated palliative care protocol in home care resulted in a significant increase in home deaths and a reduction in hospital use and costs. Insurance data was pivotal for regional follow up of palliative patients.

Abstract ID: P01:10

Abstract type: Poster

Family Caregivers' Experience of Communication With Nursing Home Staff From Admission to End-Of-Life During COVID-19 Pandemic: A Qualitative Study Employing a Transitional Perspective

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Background/aims: Family caregiving in nursing home (NH) moves across three main transition phases, including

- (i) transition to long-term care,
- (ii) deterioration-in-condition, and
- (iii) end-of-life.

Person-centered communication is recognized to be of help over the entire institutionalization period. However, during COVID-19 pandemic traditional modalities of in-person communication have been largely replaced by remote communication, creating challenges to meaningful engagement. Therefore, this study explores family caregivers' experience of communication with NH staff during COVID-19 pandemic from admission to end of life.

Methods: Descriptive qualitative study with inductive content analysis. Semi-structured in-depth interviews involved 25 family caregivers at different phases of their caregiving trajectory (8 in the transitional phase, 10 in the deterioration-in-condition phase, and 7 in the end-of-life phase) across 7 North-west Italian NHs.

Results: Regardless the phase of caregiving trajectory, what mattered the most to family caregivers was the opportunity to have regular and skilled compassionate communication with healthcare professionals, even if the need of in-person communication increased nearing death. COVID-19 pandemic enhanced family caregivers' need to interact with healthcare professionals they trusted and had established a relationship with. Knowledge of residents' care preferences mitigated family caregivers' decision-making burden over caregiving trajectory.

Conclusions: Despite in-person contacts being preferred and facilitated when possible particularly at the end of life, meaningful communication can occur also through remote modalities. Investments in training healthcare professionals about effective long-distance communication and supportive skills can help trusting relationships to be established. Open discussions about residents' care preferences should be encouraged.

Abstract ID: P01:11

Abstract type: Poster

Assessing Mealtime Environments in Nursing Homes – Development and Validation of an Observation Protocol

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Background/aims: Nutritional problems are a common cause of health problems in the older population. In nursing homes there are challenges working with nutritional problems due to the complexity of the residents' diverse preferences. The diversity is caused by, for example, different nutritional needs depending on palliative stage both in regards to intake of nutrients and the social significance of the mealtime. Five aspects meal model (FAMM) is a theoretical framework highlighting how different aspects separately and jointly influence the experience of mealtime. FAMM arranges mealtime experience in five aspects: room, meeting, product, management control system and atmosphere.

Aim: To further develop and validate an observational instrument, originating from the theoretical framework FAMM, to be used in mealtime environments in the context of nursing homes.

Methods: Content validity index was used to validate the development of the instrument. Personnel, residents, and residents' next of kin in a nursing home took part in the initial development together with researchers. Next experts assessed the relevance of the items and item content validity index (I-CVI), scale CVI (S-CVI) and modified Kappa were calculated. Comments from the experts, were used to ensure the instruments comprehensibility.

Results: The calculations displayed high validity of the items. I-CVI and modified kappa also indicated coherence between the experts' assessments. Changes in the structure and phrasing were made according to comments given by the experts. The adjustments made resulted in a distinct structure in reference to FAMM.

Conclusions: Using an existing observational instrument gave the process of identifying items of relevance a foundation to proceed from, and the use of FAMM gave a foundation for the structure of the instrument. To overcome issues regarding the possibility of chance agreement, modified Kappa and S-CVI were used and the ratings were considered as high.

Abstract ID: P01:13

Abstract type: Poster

Barriers and Facilitators to Implement Family Carer Decision Support Intervention Using Family Care Conferences in Nursing Homes in the Czech Republic: National Data From Mysupport Study

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Background/aims: Providing end of life care for people with advanced dementia in nursing homes is especially challenging for staff as they need to involve family caregivers in the decision making process. Family Carer Decision Support (FCDS) is an educational intervention that helps staff in involving family carers in advance care planning (ACP) using family care conferences. The aim of this study was to screen possible barriers and facilitators that may help or hinder the process of implementation of this intervention in nursing homes.

Methods: We interviewed 2 care home managers (n= 2), 9 members of staff and 3 family caregivers of residents with advanced dementia before starting the implementation phase of mySupport study. Semi-structured interviews were analysed using thematic analysis using deductive approach.

Results: We identified barriers related to care home staff (different competencies in staff in delivering information about health condition of residents, e.g., social worker vs nurses); barriers related to family carers (denial, conflicts in family, low motivation to ACP discussions, fear of death and dying) and logistic barriers (scheduling difficulties, lack of time). Several factors were identified as facilitators in the same categories: related to care home staff (education, organizational culture, experience with palliative care, motivation); family carers (high motivation) and logistic facilitators (using videoconferences).

Conclusions: Involving family carers in ACP is essential in residents with dementia and we should be aware of possible conflicts in families or their fear of these discussions and address these issues before inviting them to family care conferences. Strengthening the motivation of staff and introducing palliative approach in the organization culture can further improve implementation of interventions such as FCDS.

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Abstract ID: P01:14

Abstract type: Poster

Quality of Life of Greek Patients With Advanced Cancer in Hospital Settings. A Descriptive Comparative Study

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Background/aims: In Greece, patients with advanced cancer are cared in hospitals due to lack of palliative care services.

Aim: To measure the quality of life of patients with advanced cancer in hospitals.

Methods: Data was collected in an oncology hospital. Patients with advanced disease, >18 years old and able to communicate were included. Participants completed the Greek validated European Oncology Research and Treatment of Cancer-Palliative (EORTCQLQ-C15-PAL(v1)) at admission (T₀) and a week later (T₁).

Results: Fifty patients (response rate 98%) participated. Prevalent cancer diagnoses were lung (34.0%), head & neck (24.0%) and breast cancer (14%). There were multiple concurrent reasons for patients' admissions, mainly pain (30%), infection (26%) and treatment side effects (24%). Most patients were at a deteriorating disease phase (62.0%) (p=1.000) and with a low performance status (mean ECOG(T₀)=2,92 vs ECOG (T₁)=2.96, z=-1.00, p=0.625) in both measurements. Fatigue (mean T₀ 72.6 vs T₁ 71.1) (z=-0,66, p=0.520), Pain (mean T₀ 56.3 vs T₁ 56.0) (z=-0.16, p=0.912) and Appetite loss (mean T₀ 55.8 vs T₁ 51.3) (z=-1.18, p=0.118) found as the key patients' problems at admission and remained

stable one week later. Statistically significant improvement was found at Dyspnoea (mean T₀ 46.0 vs T₁ 37.3) (z=-2.84, p=0.007); Insomnia (mean T₀ 48.0 vs T₁ 42.86) (z=-2.32, p=0.035); Nausea & Vomiting (mean T₀ 16.0 vs T₁ 9.7) (z=-2.16, p=0.029). Although patients reported poor Global health status/quality of life (T₀ 29.0 vs T₁ 29.7) (z=-0.47, p=0.593) and low Physical functioning (T₀ 42.4 vs T₁ 44.0) (z=-0.45, p=0.663), the reported mean score (0-100) was high for Emotional functioning (T₀ 72.8 vs T₁ 73.7) (z=-0.43, p=0.691). No statistically significant improvement was found at T₁.

Conclusions: Hospitalized Greek patients with advanced cancer experience a good emotional wellbeing despite high intensity of symptoms and poor quality of life. Further search is needed to explain this paradox.

Abstract ID: P01:15

Abstract type: Poster

Patient-Centred Care in the Last Year of Life: Using Co-design to Develop a Two-Sided Trigger Question-Based Intervention in Acute Hospitals

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Background/aims: General hospital units are the most important checkpoints for transitions in the last year of life. Yet, satisfaction with hospitals is the lowest of all health service providers. To optimize patient-centered care in acute hospitals, we aim to test an intervention for hospitals using a two-sided (healthcare professionals (HCPs) and patients) trigger question-based intervention. Co-design ensures that the research is relevant to the populations it will affect.

Aims: Tailor and adapt a two-sided intervention and develop an implementation strategy involving HCPs and patient representatives.

Methods: Qualitative interviews were conducted with HCPs (n=7) and patient representatives (n=3) involved in end-of-life care. The semi-structured interview guide comprised (I) experiences, attitudes and requirements concerning the identification and standardised care of people in the last year of life, (II) presentation of the planned intervention, (III) barriers and facilitators for implementation. Data was analysed with MAXQDA.

Results: The experts' recommendations include providing information on objectives, responsibilities, program components and conducting workshops; raising awareness of end-of-life care and illustrating personal benefits; participation opportunities and support mechanisms with feedback loops; close contact between adopters and implementers; frequent reminders about the intervention using different approaches; considering HCPs workload through an add-in approach to facilitate integration into daily routines.

Conclusions: The co-design process contributes to the production of high-quality research beneficial to patients and the health service. In response to the experts' suggestions, an implementation strategy was developed incorporating characteristics of the intervention, implementers and users, the organisation and the quality and location of information provision.

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Abstract ID: P01:17

Abstract type: Poster

The Sinclair Compassion Questionnaire (SCQ): A Valid and Reliable Patient Reported Compassion Measure

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Background/aims: Compassion is considered a central pillar of quality palliative care, however there is a lack of psychometrically robust compassion measures impeding research on the topic and compassionate care. We developed a valid and reliable compassion measure, the Sinclair Compassion Questionnaire (SCQ), for use in palliative care, hospice and longterm care.

Methods: After generating candidate items in accordance with measure and development guidelines, subject matter experts and members of our patient advisory group evaluated the content coverage, question stems, response scales and items prior to conducting cognitive interviews with patients. The draft 54 item measure was then administered to 303 patients in the Exploratory Factor Analysis (EFA), with 65 patients having the measure readministered 24 hours later to assess test-retest reliability. In the Confirmatory Factor Analysis stage the SCQ was administered to 330 patients, along with the ESAS-r; the Picker Patient Experience Questionnaire and the Schwartz Centre Compassion Care Scale to test convergent and divergent validity.

Results: The EFA and CFA revealed the 15-item SCQ loaded on a single factor, with factor loadings between 0.76 and 0.86, test-retest reliability (0.74-0.89), and internal reliability (Cronbach's Alpha 0.961). The SCQ was positively correlated with the SCCCS ($r=0.75$, $p<0.001$) and PPEQ ($r=0.60$, $p<0.001$). Patients reporting higher experiences of compassion had significantly lower depression and higher well-being on the ESAS-r. The SCQ is available in English and French, with a Spanish version currently being validated. This study also validated a SCQ Short Form (SCQ-SF) and also produced the SCQ-i, which assesses individual preferences of compassion in order to tailor compassion in a personalized manner.

Conclusions: The SCQ provides researchers with a tool to develop compassion interventions, while providing clinicians a valid and reliable psychometric to assess compassion on a routine basis, improving quality care in the process.

Abstract ID: P01:18

Abstract type: Poster

Implementation and Evaluation of a Palliative Care Inpatient Unit's Delirium Guidelines: A Service Improvement Project

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Background/aims: Delirium is characterised by acute onset of fluctuating confusion and altered conscious level. It is common in palliative patients and associated with worse outcomes. Recognition and management of delirium is poorly supported in palliative care units. This project aimed to produce sustainable improvement in delirium care in an inpatient hospice unit.

Methods: This service improvement project used a behaviour change Theoretical Domain Framework and Normalisation Process Theory based approach comprising one intervention and two evaluation stages

and co-design of a refined intervention. A mixed-methods evaluation gathered data from: case-note review, staff surveys and interviews. The first intervention modified delirium guidelines by introducing the 4AT screening test and simplifying the symptom severity assessment. Guidelines were integrated into the electronic record system and 'delirium champions' appointed for sustainability. The second intervention was co-designed targeting barriers and facilitators to guideline implementation and focussing on sustainability.

Results: The first intervention delivered improvement in delirium episodes diagnosed (19% to 39%), receiving systematic assessment of reversible causes (33% to 52%) and managed appropriately with non-pharmacological interventions (17% to 59%). Where risk assessment was conducted, 89% of patients were high-risk. The co-design developed an intervention focussing on a hospice-wide "delirium-friendly" environment and 4AT screening as the pathway to guideline-adherent delirium care. Many elements are applicable to other palliative care inpatient settings.

Conclusions: A theory-driven approach to complex intervention design and implementation is feasible in a hospice setting. Given the high-risk of delirium in hospice in-patients, applying delirium risk reduction strategies to *all* seems appropriate. Delirium screening appears to be a "gateway" component of delirium care, facilitating delirium recognition and guideline-adherent delirium management.

Abstract ID: P01:19

Abstract type: Poster

A Sip or a Glug? Exploratory Mixed Methods Study of Behaviours of Patients Who Take Their Strong Opioids as Unmeasured 'Glugs'

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Background/aims: Some patients take their liquid strong opioid breakthrough painkillers as unmeasured glugs. The volume people take as glugs can vary but we do not know how volumes vary for liquid medications.

Aims: To investigate how and why patients take their strong opioid painkillers as unmeasured glugs.

Methods: Mixed methods – A phenomenological approach was used to examine the experiences of patients who take their strong opioid liquid medication as an unmeasured 'glug'. Qualitative interviews were conducted using a topic guide and interview transcripts were thematically analysed. Measurement of the mass of 2 unmeasured glugs per patient were recorded.

Results: Only two of 16 patients were taking within 20% of the correct dose of their breakthrough liquid strong analgesia. Many varied the dose depending on the severity of the pain episode. Convenience, confusion about the correct dose, and issues with spoons were the other main reasons for people choosing to glug.

Conclusions: This is the first published study exploring the behaviour of patients who take their strong analgesia as unmeasured glugs. Knowing that these patients are likely to be taking an incorrect dose, and the reasons behind glugging may help clinicians to help these patients to manage their pain better.

Abstract ID: P01:20

Abstract type: Poster

Implementation of Clinical Guidelines in Clinical Practice. Data From a National Quality Improvement Project in Specialized Palliative Care

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Background/aims: A national project following the 'Improvement Model' aimed at improving the quality of life of patients admitted to the 44 specialized palliative care (SPC) services in Denmark by increasing adherence to clinical guidelines for pain, dyspnea, constipation and depression. The 'delivery of a symptom package' was defined as provision of care according to the guideline for patients with severe levels of a symptom. We aimed at investigating to what extent clinicians implemented the four guidelines by evaluating 1) the proportions of patients admitted to SPC who qualified for (reported severe levels of symptoms) and received each symptom package, 2) the proportions of SPC services implementing and delivering the four symptom packages over time, and 3) how often different interventions were given to patients receiving symptom packages.

Methods: This project included adult cancer patients starting SPC between September 2017 and June 2019 and completed the EORTC QLQ-C15-PAL questionnaire. Data was collected from the Danish Palliative Care Database.

Results: Among 18,379 patients admitted to SPC during the project, 11,330 (62%) completed the questionnaire. Across the project, the symptom packages were delivered to 60% of those with pain and to 54%, 56% and 32% of those with dyspnea, constipation and depression, respectively. During the first 6-9 months, there was a steady increase in the proportions of patients receiving the symptom packages reaching around 77-86%, except for depression (54%). Pain and constipation were most often treated pharmacologically (66-72%), whereas dyspnea and depression were most often treated non-pharmacologically (61%).

Conclusions: Overall, the project was successful in increasing the implementation of clinical guidelines for physical symptoms but less so for depression, and with considerable differences between SPC services. The project generated national data about the types of interventions delivered that may be used to understand differences in care and outcomes.

Abstract ID: P01:21

Abstract type: Poster

Care Needs and Provision in Dutch Hospices: A Retrospective Cross-Sectional Study Focusing on Care Across the Three Different Hospice Types in The Netherlands

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Background/aims: 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). There are variations in organisation and staffing between these facilities, which may translate to differences in care processes, provision, and outcomes. The aim of this study was to describe care processes and provision in Dutch hospice care.

Methods: A retrospective cross-sectional study using clinical records, incorporating 51 hospices. For each patient, data was collected detailing processes of care (such as multidisciplinary meetings, reporting instruments or care plans) and care provision.

Results: In total 803 patients were included from 51 hospices, mean age 76.1. Patients admitted to SA hospices were more likely to have structured care processes such as multidisciplinary meetings (37%, 6% VDH, 14% HU) and individual care plans (91%, 43%, 57% respectively) employed. Care provision focused primarily on physical care needs, with mean 2.9 physical issues identified at admission, compared with 0.7

psychological, 0.2 social and 0.1 spiritual issues documented. The use of an individual care plan at admission resulted in increased care provision through identification (median 4.0 vs 3.0, $p<0.001$), use of medication (2.0 vs 1.0, $p=0.002$) and non-medication (1.0 vs 0.0, $p<0.001$) interventions, monitoring (2.0 vs 1.0, $p<0.001$) and evaluation (0.0 vs 0.0, $p=0.002$). Those patients whose care was discussed at multidisciplinary meetings received similar increases in identification of clinical issues, medication interventions, monitoring and evaluation. These increases were most apparent for clinical problems related to the physical and psychological dimensions.

Conclusions: Care processes vary between hospices and hospice types. The implementation of structured care processes may facilitate the identification and treatment of patient's care needs, potentially improving the quality of care.

Abstract ID: P01:22

Abstract type: Poster

Supporting Recovery and Anticipating Nearness of End of Life for Older Adults With Frailty and Multimorbidity Requiring Intermediate Inpatient Care Between Hospital and Home; A Feasibility Evaluation

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Background/aims: Intermediate Care Units deliver multidisciplinary care for mainly older adults in transition between hospital and home. Patients' care needs are numerous with often uncertain outcomes associated with multimorbidity and frailty. How to deliver optimal care is uncertain.

Aim: To evaluate the feasibility of an intervention pathway using evidence-based tools to manage care and during clinical uncertainty for older adults with frailty from admission to discharge on clinical outcomes and processes.

Methods: Mixed methods pre-post feasibility evaluation of an intervention using evidence-based tools to manage care and during clinical uncertainty in two intermediate care units with patients aged ≥ 65 years. The intervention sort to identify and manage frailty by using a brief-Comprehensive Geriatric Assessment and Clinical Frailty Scale with three scores (pre-admission, on admission and 3-month projection) to promote person-centred care. Evaluation measuring patient outcomes, experiences and economic impact, and process with audit of intervention delivery and practice observations.

Results: N=40 patients recruited with mean age 83.5 years (SD 8.0), 72% lived alone and 54% had no primary carer. All transferred from an acute hospital. 87% level of frailty declined between pre-admission (average mild) and admission (average moderate). No change in frailty level for patients severely frail (n=3). Intervention delivery by advanced clinical practitioners within the multi-disciplinary team increased identification of patients' needs and priorities for care, such as advance care planning. The frailty scores formed a shared language across disciplines to identify goals of care and drive interdisciplinary working.

Conclusions: It is feasible to implement an evidence-based service pathway from admission to discharge to deliver person-centred evidence-informed care at the point of care. The tools formed a shared language for goal driven care and interdisciplinary working.

Abstract ID: P01:23

Abstract type: Poster

The Need for Day Hospices and Palliative Day-Care Clinics in the German End-Of-Life Care Landscape: A Qualitative Study

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Background/aims: Compared to countries such as Great Britain, where day hospices and palliative day-care clinics are an integral part of the end-of-life care landscape, there are hardly any such facilities in Germany: Only 13 day hospices and 5 palliative day-care clinics are operating; 12 and 3, respectively, are under construction. To which extent is there a need for these facilities and how are they locally connected? This study's aim is to gain insights into the need for hospice and palliative day-care facilities as well as information about their integration into the German end-of-life care landscape from an internal facility perspective.

Methods: Four heterogeneous facilities were selected to cover different aspects of day-care services in Germany (2 day hospices; 2 palliative day-care clinics). Eight semi-structured telephone interviews with facility managers and administrative staff were conducted. Transcripts of the audio-recorded interviews were analyzed according to Mayring's qualitative content analysis.

Results: The interviews lasted 48 minutes on average. From the facility staff's perspectives, hospice and palliative day-care facilities close existing care gaps, meet patients' desire to avoid inpatient admissions and provide relief for family caregivers. Moreover, interviewees described networking within the hospice and palliative care landscape as crucial, occasionally reporting other providers' fears that day-care services would compete with other services.

Conclusions: Results suggest that hospice and palliative day-care facilities can fill gaps in end-of-life care. Good integration into the care network seems to reduce other providers' prejudices and promote cooperation. To ensure that day-care services complement the existing end-of-life care landscape in a needs-oriented way, external perspectives of other providers as well as patients' and family caregivers' preferences should also be surveyed.

Abstract ID: P01:24

Abstract type: Poster

Good Grief Festival: Evaluation of a UK Public Engagement Initiative on Grief and Bereavement

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Background/aims: Good Grief Festival was initially planned as an inclusive face-to-face festival on the topic of grief. Due to COVID-19, the festival was held online over 3 days in October 2020. We aimed to evaluate the festival's reach and impact.

Methods: A pre/post evaluation was conducted via online surveys. Pre-festival surveys assessed reasons for attending and attitudes to bereavement across 4 items (being scared of saying the wrong thing, avoiding talking to someone bereaved, knowing what to do if someone bereaved was having trouble, knowing what kind of help/support to offer). Post-festival surveys evaluated audience experiences and the 4 attitude items.

Results: 8500+ people attended, with most attending 2-5 events. Pre-festival survey participants (n=3785) were mostly women (91%) and White (91%). 9% were from Black or minority ethnic communities. 14% were age \geq 65 years, 16% age \leq 34 years. 44% were members of the public. A third had been bereaved in the last year; 6% had never been bereaved. People attended to learn about grief/bereavement (77%), be inspired (52%) and feel part of a community (49%). Post-festival participants (n=685) reported feeling part of a community (68%), learning about

grief/bereavement (68%) and being inspired (66%). 89% rated the festival as excellent/very good. 75% agreed that through attending they felt more confident talking about grief. Higher ratings and confidence were associated with attending a greater number of events. Post-festival attitudes were significantly higher across all 4 items ($P < 0.001$). Free-text data showed appreciation e.g., for the online format, connection in the context of lockdown and speakers' ethnic diversity. Suggestions included improving registration, more interactive/arts-based events and reducing the volume of content.

Conclusions: Good Grief Festival was successful at reaching a large public audience, with data indicating benefit in terms of engagement, confidence and community-building. The evaluation was critical in shaping future events.

Abstract ID: P01:25

Abstract type: Poster

Integrating Palliative Care in the Intensive Care Unit; A Systematic Review

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Background: Despite technological advances, mortality in Intensive Care Units (ICUs) remains significant. Delayed identification of dying, inadequate symptom control and inadequate family support have been reported. The integration of palliative care (PC) in ICUs has been proposed as a way forward.

Aim: To evaluate the types of PC interventions implemented in the ICU and assess the impact of integrating PC in ICU practice.

Methods: A systematic review; (protocol published in PROSPERO; ID: CRD42018094315). The databases Medline, Embase, Cochrane, CINAHL, PsycINFO were searched from inception to 2021. Additional reference lists, consensus guidelines were searched. Selected studies were included, if they involved adults (age \geq 18 years) admitted to an ICU, receiving a PC intervention. Eligible studies included controlled trials (randomised and non-randomised). Study screening was performed by two independent reviewers and quality was assessed using the ROBINS and ROBINS-I tools.

Results: Nine randomised and 49 cohort studies were included. Five types of interventions were identified: communication, ethics consultations, educational, palliative care team involvement and advance care planning. Thirty studies proposed an integration approach, whilst 28 suggested a consultative model. The most frequently reported outcomes were ICU/hospital length of stay (60%), limitation of life-sustaining treatment decisions (40%) and mortality (27.2%). Consultation interventions showed higher impact on ICU and hospital length of stay, whilst the consultative model was associated with a greater number of limitations of life sustaining treatments decisions.

Conclusions: Beneficial effects were associated with active palliative care involvement strategies. However, their effectiveness was limited by heterogeneity of interventions and outcomes. More focus on the under-represented outcomes is required. Moreover, standardised outcomes with validated metrics and patient-centered focus should be prioritized, to allow meaningful comparisons.

Patient Population

Abstract ID: P02:01

Abstract type: Poster

"I Am Not Afraid to Ask the Question, I Am Afraid of the Answer"
Challenges of Healthcare Professionals in Providing Care to

Adolescents and Young Adults With an Uncertain And/or Poor Cancer Prognosis

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Background/aims: Adolescents and Young Adults (AYAs, ages 18-39 years) with advanced cancer have an increased life expectancy due to improvements and refinements in cancer therapies, resulting in a growing group of AYAs living with an uncertain and/or poor cancer prognosis (UPCP). To date, no studies have examined the challenges of Health Care Professionals (HCPs) working with AYAs with UPCP. This study aims to understand the challenges and barriers in daily clinical practice experienced by HCPs from different disciplines who provide palliative as well as general care to AYAs with UPCP.

Methods: Using a qualitative descriptive design, semi-structured interviews were conducted with HCPs from a variety of backgrounds (e.g., nurses, (neuro)-oncologists, psychologists). Interviews were transcribed verbatim and analyzed using reflexive thematic analysis with an inductive orientation.

Results: Forty-nine HCPs were interviewed. They had on average 13 years of clinical work experience with AYA care and the majority saw ≥ 10 new AYAs per year. Overall, we found that the threat of premature death within this young patient group increased emotional impact on HCPs and evokes a feeling of unfairness, which was an extra motivation for HCPs to provide the most optimal care possible. We generated four themes regarding the challenges HCPs experienced: (1) emotional confrontation, including identification with AYA and feeling helplessness. (2) Making and maintaining contact with AYAs regarding discussing sensitive topics, challenging patient groups and consultation room compositions. Furthermore, HCPs struggled with (3) uncertainty around prognosis and (4) obstacles in the healthcare organization.

Conclusions: HCPs experienced unique emotional and practical challenges when providing care to AYAs with UPCP. The results from this study highlight the need to develop training and support for HCPs treating AYAs with UPCP to increase their own well-being and optimize the delivery of the most optimal person and age adjusted care.

Abstract ID: P02:02

Abstract type: Poster

Epidemiology of Pain Among Patients With Solid Metastatic Cancer During Last Year of Life

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Background/aims: Despite medical advancements, pain is a major source of suffering at the end of life for patients with a solid metastatic cancer. We aimed to assess the trajectory of pain prevalence, severity, interference and inadequacy of analgesia through the last year of life.

Methods: We analyzed data from the last year of life of 345 decedents from a prospective cohort study of 600 patients with a solid metastatic cancer in Singapore. Patients were surveyed every 3 months and their pain outcomes (prevalence, severity and interference) and inadequacy of analgesia were analyzed. We used mixed-effects regressions to assess association of pain outcomes with patients' time from death, demographics and after a planned or unplanned hospitalisation.

Results: Prevalence of pain steadily increased from 41% at 11-12 months to 65% in the last two months before death. Pain severity and interference scores (mean \pm SD) also slowly increased through the last year of life (12 months before death: severity: 1.4 ± 2.0 ; interference: 1.4 ± 2.0 ; last month: severity: 2.5 ± 2.6 ; interference: 2.6 ± 3.0). Pain outcomes were significantly worse (p -value < 0.05) for younger patients, those with higher education and more financial difficulties, and interference was higher after an unplanned hospitalisation in the last month. For patients reporting moderate to severe pain, inadequacy of analgesia decreased from 83% at 11-12 months to 43% in the last two months before death.

Conclusions: Findings highlight the need for greater attention in monitoring and treatment of pain even earlier in the disease trajectory, and increased attention to patients discharged from an unplanned hospitalisation.

Funding: This work was supported by Singapore Millennium Foundation and Lien Centre for Palliative Care (LCPC-IN14-0003).

Abstract ID: P02:03

Abstract type: Poster

Prevalence and Overlap of Malnutrition, Sarcopenia, and Cachexia in Hospitalised Older Adults With Cancer: A Cross-Sectional Study

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Background/aims: Malnutrition, sarcopenia, and cachexia are three under-recognised and under-treated conditions. We aimed to investigate the prevalence and overlap of these conditions in a cohort of older adults with cancer.

Methods: A prospective, cross-sectional, exploratory study. Eligible patients were consenting adults with cancer, aged ≥ 70 in a tertiary centre, recruited January to March 2020. Participants were screened for malnutrition, sarcopenia, and cachexia using the 3-Minute Nutrition Screening tool (3-MinNS), revised European working group on sarcopenia in older people (EWGSOP2) algorithm and Mini cachexia score (MCASCO). Descriptive analysis and associations between the conditions and key clinical outcomes were performed, including logistic regression.

Results: Of the 30 participants (70% male, mean age 75.7yrs, range 70-83), 13 (43.3%) were severely malnourished, 16 (53.3%) sarcopenic, and 17 (56.7%) cachexic. 80% had at least one of the conditions. 7 (23.3%) were diagnosed with all three conditions. In univariate analysis i) Rockwood clinical frailty score (OR 2.94 [CI:1.26-6.89, $p=0.013$]) was associated with sarcopenia, ii) reported percentage meal consumption (OR 2.28 [CI:1.24-4.19, $p=0.008$]), and visible wasting (OR 8.43 [CI:1.9-37.3]) were associated with malnutrition, and iii) Percentage overall weight loss (OR 8.44 [CI:1.91-37.31]) was associated with cachexia. Low to moderate correlations were seen between different nutrition screening tools: MUST and 3-MinNS (correlation coefficient 0.49), PG-SGA and 3-MinNS (correlation coefficient 0.60).

Conclusions: Malnutrition, sarcopenia, and cachexia are highly prevalent conditions in hospitalised older adults with cancer, with one or more condition affecting the majority of patients. Screening for these conditions is feasible in a hospital setting, and may be simplified using key markers of the conditions. Further investigations into the clinical utility of simplified screening tools, able to distinguish between the three conditions, are needed.

Abstract ID: P02:04

Abstract type: Poster

Palliative Care Referral Criteria: A Scoping Review of the Literature

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Background/aims: Background. It is known that early palliative care (PC) can improve patients' quality of life, therefore identifying appropriate criteria to refer patients (pts) to PC is relevant for the implementation of oncology and PC integration.

Aim: To identify and map available evidences regarding operational criteria to refer cancer pts to timely PC.

Methods: Method. A scoping review was performed, consulting PubMed database, in the period between Jan 2014 and Dec 2020 to follow up a previous systematic review (Hui et al 2016). The search strategy included the use of the terms "cancer", "referral", "needs", "palliative care" and "supportive care". Three researchers reviewed the citations for inclusion and extracted the studies including referral tools.

Results: Results. From the initial 3241 items retrieved, 77 full text articles were examined; 11 articles were added from hand search and grey literature. 17 eligible papers included several PC referral tools which were quite heterogeneous in length (from 7 to 32 items) and in the criteria used. The most frequently used criteria were: uncontrolled symptoms (11/17), poor performance status (10/17), prognosis/diagnosis (7/17), and comorbidities (5/17). In 14/17 studies data were reported by physicians or nurses, in 13/17 tools were validated and 4/17 included patient reported outcomes.

Conclusions: Conclusion. The definition of standardized criteria for PC referral is still open to research. This scoping review has shown a heterogeneous use of criteria for referral to PC and is the starting point for drawing up a list of criteria that will be used together with multidisciplinary and multiprofessional consensus to build a referral system to be tested in an implementation study.

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Abstract ID: P02:05

Abstract type: Poster

Palliative Radiation Therapy for Painful Bone Metastasis in Times of COVID-19

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Background/aims: Radiation therapy is critical for the treatment of painful bone metastases, providing an improvement in the quality of life of cancer patient. During the coronavirus disease 2019 (COVID-19) pandemic period, radiation oncologists have adapted to the situation, modifying the fractionations to shorter schedules, to prevent the risk of infection in palliative patient.

Methods: Patients who receive antialgic palliative radiotherapy for painful bone metastases from March 2020 to March 2021 were

reviewed. In this review we analyze the evolution of treatment schedules in related to the pandemic, as well as other data of interest related to the treatment.

Gy/fr	Daily fraction	% patients
8	1	24.16
6	1	3.37
5	4	3.93
4	5	55.62
3	10	11.80
2	20	1.12

Results: 178 patients were analyzed, with an average age of 68 years (36-93 years). 67.42% patients were males and 32.58% females. Most frequently primary tumors were 38% lung, 21% prostate and 18% breast. Pain bone metastasis were diagnosed as a debut symptom in 19 patients (10.67%). 7 patients (3.93%) required reirradiation. 110 patients (68%) died. Treatment schedules were: 99 patients (55.62%) received 5 fractions of 4Gy, 43 (24.16%) single fraction of 8Gy, 21 (11.80%) 10 fractions of 3Gy. Months with the highest incidence by COVID-19 were used shortest divisions and single session treatments.

Conclusions: Cancer pain is one of the main reasons for radiotherapy treatment. During the pandemic, patients have been diagnosed in more advanced stages, in many cases as metastatic disease. Therefore, the need for treatment has increased. The option of shorter schedules is beneficial for the patient, since by reducing visits to the hospital the risk of infection decreases, without worsening the effectiveness of the treatment.

Abstract ID: P02:06

Abstract type: Poster

Our Experience in Palliative Radiotherapy During the COVID-19 Pandemic

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Background/aims: Radiotherapy is an effective palliative treatment for metastatic disease. The current COVID-19 pandemic has led us to consider shorter courses, new guidelines and prioritize cases clinically urgent. The purpose of this study is to analyze our practice in palliative treatment, new potential strategies and hypofractionation.

Methods: 252 patients who receive palliative radiation treatment from March 2020 to March 2021 were reviewed. We analyze how the treatment line has been modified throughout the 1 year of the pandemic and other items related to the different therapeutic options as mortality, reirradiation, primary localization and intention.

Results: Median age was 68 years (range 33-95y), 66% males, 34% females. Main primary tumors were 30% lung, 12% prostate and 10% breast. 65% patients had painful bone metastases, 15% brain metastases, 14% cord compression, 4% bleeding and 2% superior vena cava obstruction. Advanced disease was detected in 12% as debut. Half of patients were treated in the two first months of the pandemic than later.

Treatment provided was:

Gy/fr	Daily fraction	%patients
8	1	27
6	1	5
5	4	4
4	5	43
3	10	20
2	20	1

8 patients required reirradiation. Currently, 66% died.

Conclusions: Radiotherapy plays a critical role improving quality of life in patients with advanced disease, even in the midst of the COVID-19 pandemic.

During the first months of confinement, short radiation therapy cycles prevailed over the long ones, as the normal schemes of fractionation coinciding with a greater number of sessions gained importance as time went on.

Abstract ID: P02:07

Abstract type: Poster

Radiotherapy for Painful Bone Metastases: Analyzing Our Practice

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Background/aims: Palliation of painful bone metastases encompasses a significant portion of radiation treatments. The COVID-19 pandemic has led us to consider shorter courses and hypofractionation. The purpose of this study is to analyze our practice: efficacy of single-fraction vs standard multifraction radiotherapy for alleviation of pain in patients with bone metastases.

Methods: 178 patients who receive radiation treatment for painful bone metastases from March 2020 to March 2021 were reviewed. We analyze rate of re-irradiation and how the treatment line has been modified throughout the 1 year of the pandemic.

Results: Median age was 68 years (range 36-93), 67% males, 33% females. Main primary tumors were 40% lung, 13% prostate and 32% breast. Advanced disease was detected in 11% as debut.

Treatment provided was:

Gy/fr	Daily fraction	%patients
8	1	24
6	1	3
5	4	4
4	5	56
3	10	12
2	20	1

Only 8 patients required reirradiation, 75% of them had received single fraction. Currently, 62% died.

Conclusions: Painful bone metastases is not an oncologic emergency but requires Radiotherapy for symptom management.

Radiotherapy has improved quality of life in patients with advanced disease in the midst of the COVID-19 pandemic, when short radiation therapy cycles prevailed over the long ones.

Almost single-fraction has shown to be an effective treatment option for patients with painful bone metastases, conventional multifraction should be considered for patients expected to have relatively long survival.

Abstract ID: P02:08

Abstract type: Poster

A Mixed Methods Study to Evaluate the Use of a Palliative Care Referral “Triggers” Tool and the Associated Integrated Palliative Care-Oncology “Triggers” Service for Outpatients With Cancer

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United Kingdom, ⁶Brighton and Sussex University Hospitals NHS Trust, Brighton, United Kingdom, ⁷University of Sheffield, Department of Oncology and Metabolism, Sheffield, United Kingdom, ⁸Royal Marsden NHS Foundation Trust, Thoracic Oncology, London, United Kingdom, ⁹Royal Marsden NHS Foundation Trust, Medical Oncology, London, United Kingdom

Background/aims: Early integration of palliative care (PC) has proven benefits. Identification of patients with the greatest need for referral remains a challenge.

Aim: To evaluate a brief seven-item centre-developed “Triggers” tool in identifying cancer patients for PC referral and to explore staff and patients’ experience of the integrated oncology-PC service based on the tool.

Methods: Single-centre, cross-sectional, observational, mixed-methods study of outpatients with lung, upper gastrointestinal or sarcoma cancers. Patients were categorised as “Triggers” tool positive or negative (T+, T-). The study was powered to observe a target tool sensitivity of 80% (5% alpha and 80% power), based on PC needs (using the Integrated Palliative Outcome scale, IPOS).

Semi-structured interviews were carried out using a modified Grounded Theory approach.

Results: 348 outpatients not known to PC were recruited, 53% T+. 92% had significant PC needs. The mean (standard deviation) IPOS score for physical symptoms was higher in T+, 8.53 (6.24), than T- patients, 6.22 (4.83), $p < 0.001$. The sensitivity of the tool was 53.7% (95% CI 48.0 – 59.3%). Survival (Kaplan Meier, log-rank test) of T+ was lower than T-, $p < 0.001$; median (95% CI) T+ 11.7 (9.7 – 15.6), T- 20.8 (18.9 – NR) months.

19 patients and 16 oncology staff were interviewed. Staff felt that the “Triggers” tool was easy to use, normalised PC in oncology clinics, enabled immediate access to experts and removed subjectivity in PC referrals. Perceived organisational barriers included time and physical space constraints. Patients recognised the joint working between the oncology and PC teams. They described their experience of PC as supporting them to live well and stressed the importance of individualising the introduction, timing, and content of PC involvement.

Conclusions: Most cancer outpatients have PC needs. The use of the “Triggers” tool normalises PC and can be used to triage patients who may benefit most from timely referral.

Abstract ID: P02:09

Abstract type: Poster

Do Cancer Centres Routinely Assess Patients’ Quality of Life— And if So, How and for What Purpose?: A Cross-Sectional Study in the Cancer Centre Network of the European Palliative Care Research Centre

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Background/aims: Routinely assessing quality of life (QoL) of patients with cancer is crucial for improving patient-centred cancer care. Yet, we know little about whether or how cancer centres assess QoL from patients' perspectives in clinical practice or in research. This study aims to investigate the nature, frequency, timing, and purpose of the collection of QoL data in clinical practice and research in cancer care across cancer centres in Europe, Canada and Australia.

Methods: Cross-sectional study of the European Palliative Care Research Centre's network of 27 cancer centres in Europe, Canada, and Australia. Centre representatives identified the most suitable persons within their cancer ward and palliative care unit (PCU) to complete the online survey, which includes questions, e.g., assessment and documentation of QoL and outcomes used. In June 2021, potential respondents were invited to participate in the study via e-mail with a link to LimeSurvey. For those who had not yet responded, a follow-up e-mail was sent in October 2021.

Results: Until 27 Oct 2021, there were 16 respondents, of whom 7 work in a cancer ward, 8 in a PCU and 1 outside the hospital. Of the 7 cancer wards, only 1 routinely documents QoL for the majority of in- and outpatients for research and/or clinical practice. In 7 of the 8 PCUs, QoL is routinely measured and documented for the majority of cancer in- and outpatients for research and/or clinical practice. We found 7 different QoL outcome measures that are used for research (e.g., EORTC-QLQ-C30), while 5 are used for clinical practice (e.g., Integrated Palliative care Outcome Scale (IPOS)). Full results will be available at the 2022 EAPC congress.

Conclusions: Based on preliminary results, PCUs seem to routinely assess and document patient's QoL more often than cancer wards. Different outcomes are also used to measure QoL. Findings suggest the need to make routine assessment of QoL a standard practice in cancer centres and to develop a minimum dataset to measure patients' QoL.

Abstract ID: P02:10

Abstract type: Poster

Factors Associated With Psychosocial Functioning in Advanced Oesophago-Gastric Cancer: A Mixed-Methods Systematic Review

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Background/aims: Oesophago-gastric cancer is an aggressive disease with a high rate of recurrence and mortality. Reduced quality of life has been evidenced, however little is known about the contributing factors. This review provides new insights into the challenges faced by those on a palliative pathway and offers a preliminary indication of the factors associated with their psychosocial functioning.

This review aims to synthesize the best available evidence in relation to the psychosocial functioning of individuals with advanced oesophago-gastric cancer and their carers.

Methods: Medline, Embase, PsycINFO, and CINAHL were searched. A mixed-methods convergent segregated approach to synthesis and integration was used.

Results: A total of 7 studies were included, including 3 quantitative studies and 4 qualitative studies. The quantitative narrative findings provide preliminary indication of several factors associated with psychosocial functioning in this clinical population, including, dysphagia, the BDNF genetic variant, performance status, and best overall response. The qualitative findings shed light on a range of physical, psychosocial, and existential challenges faced by advanced oesophago-gastric cancer patients. These multiple and often persistent challenges appear to cause considerable distress, however, patients describe the importance of maintaining a sense of normality and control over their illness and its effects. Patients value continuity and structure, however many report shortcomings when accessing care.

Conclusions: Further high-quality research is needed to understand how best to support and manage the palliative care needs of individuals living with advanced oesophago-gastric cancer. Implications for practice are discussed, suggesting that psychosocial interventions, complex symptom management and continuity of care could improve the psychosocial functioning of individuals in this setting.

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Abstract ID: P02:11

Abstract type: Poster

Analysis of Methadone Prescribing for Pathological Cough in Palliative Care Patients in an Acute Hospital Setting

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Background/aims: Chronic cough may adversely affect sleep, quality of life or cause distressing symptoms such as vomiting or muscle strain. Guidelines advise antitussives if cough persists despite treatment of reversible causes. In palliative care opioid and opioid derivatives such as methadone are used as antitussives. Methadone is a synthetic opioid with a d-isomer that acts as antitussive. Methadone has a complex pharmacological profile with many safety concerns and thus practitioners are reluctant to use it.

Aims and Objectives: To identify dosage of methadone prescribed as antitussive. To establish demographics of this cohort. To evaluate if methadone is an effective antitussive using physician rated scores.

Methods: A retrospective analysis of patients prescribed methadone as antitussive between March 2020 and June 2021 was performed. Patient age, sex, baseline bloods, prescription and medical charts were reviewed. Adverse events associated with methadone were also recorded. Prescribing physician rated severity scores of cough pre and post methadone were also analysed.

Results: Thirteen patients were prescribed methadone for suppression of intractable cough. Methadone was administered as a twice daily dose and the mean dose was 6 milligram per 24 hours. No adverse side-effects were associated with methadone. The most prevalent diagnosis in this group was lung carcinoma/lung metastases, followed by oesophageal cancer. The majority (85%) were prescribed an 'other' baseline opiate prior to addition of methadone. Analysis of prescribing physician rated 'cough' severity scores revealed that methadone effectively reduced severity of cough from severe to absent or mild, which was statistically significant ($P < 0.001$).

Conclusions: It appears that methadone is an effective and well tolerated antitussive when prescribed for appropriately selected palliative patients. It is hoped that this research will promote the safe and effective use of methadone as an antitussive.

Abstract ID: P02:13

Abstract type: Poster

Perception of Healthcare Professionals on Palliative Care For Patients With Chronic Obstructive Pulmonary Disease

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Background/aims: The introduction of palliative care in the early stages of chronic obstructive pulmonary disease (COPD) prevents suffering and promotes quality of life. Patients with COPD have limited access to palliative care compared to patients with oncological diseases. Healthcare professionals (HPs) caring for COPD patients are in the best position to recognize and identify palliative care needs. The aim of this study was to describe the perceptions of HPs on palliative care provision, implementation,

access and organization. As a secondary objective we aimed to identify gaps, barriers, potential information, as well as training needs of HPs in relation to palliative care for patients with advanced COPD.

Methods: An online survey was conducted. A multidisciplinary sample (n=94) of pulmonologists, respiratory nurses, nurse assistants, care assistants and physiotherapists working in a university hospital, private practice or *Geneva lung league* were invited to participate.

Results: Fifty-seven HPs participated in this study.

The majority agrees that COPD patients need palliative care (53, 98.2%). Nine participants (17.0%) reported not knowing when to start a palliative care approach/management. The majority of the participants (43, 89.6%) do not use guidelines to identify palliative care needs in COPD patients.

The main barriers in referring COPD patients to specialist palliative care is lack of knowledge of available resources (23, 52.3%), and the feeling that their patients do not like or want to be referred to palliative care (23, 52.3%). The most commonly reported barriers in communication with COPD patients around the topic of 'end of life' were perception that the patient is not ready (28, 58.3%) and lack of skills/training (overworked team) (24, 50.0%).

HPs reported the need for short training sessions to increase their skills in palliative care.

Conclusions: A multidisciplinary perspective is needed to develop policies and a framework for the integration of palliative care for COPD patients.

Abstract ID: P02:14

Abstract type: Poster

A Comparison of the Referral Practices to Specialist Palliative Care by Cardiologists, Respirologists and Oncologists

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Background/aims: Patients with non-malignant disease have palliative care needs similar to those with cancer, yet barriers remain for their access to specialist palliative care (SPC). Referral practices to SPC of oncologists, cardiologists, and respirologists could provide insight into reasons for this difference in access. We sought to compare the referral practices to and attitudes about SPC of cardiologists and respirologists to those of oncologists.

Methods: Surveys for each specialty were created and disseminated to physicians across Canada in 2012 (oncologists) and 2018 (cardiologists and respirologists). The results of the surveys were compared descriptively.

Results: The combined response rate to the 3 surveys was 61.3% (1,592/2,598). Of the respondents, 603 were oncologists, 551 were cardiologists, and 438 were respirologists. Perceived availability of all SPC services was higher for cancer than for non-cancer patients; most prominently, perceived availability of outpatient clinics was 73.1%, 35.2%, and 38.0% for patients with oncologic, cardiac, and respiratory diseases, respectively. Oncologists were more likely to make a referral to SPC for a symptomatic patient with a prognosis of <1 year (oncology 85.5%, cardiology 46.8%, respirology 56.1%). Cardiologists and respirologists were more likely to make a referral to SPC at a prognosis of <1 month (oncology 3.4%, cardiology 29.6%, respirology 12.6%); more likely to believe that their patients had negative perceptions about SPC; and more likely to refer to SPC earlier if it were renamed supportive care.

Conclusions: For patients with cardiac and respiratory diseases, the perceived availability of SPC services in 2018 was markedly lower, and the timing of SPC referral was later, than among patients with cancer in 2012. These findings suggest that access to SPC among patients with cardiac and respiratory diseases lags behind that among patients with cancer.

Abstract ID: P02:15

Abstract type: Poster

Exploring Intention and Related Factors of Dialysis Withdrawal in End-Stage Renal Disease Patients in Taiwan

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Background/aims: Understanding renal patients' intention for withdrawing dialysis and its influential factors could enhance early palliative care intervention for symptom management. However, relevant evidence is sparse in Taiwan. The aim of this study is to explore intention and related factors to withdraw dialysis of end-stage renal disease (ESRD) patients in Taiwan.

Methods: A cross-sectional design using questionnaire to collect patient data including their demographic, symptoms (M.D. Anderson Symptom Inventory-Taiwan Form for ESRD), health status (12-Item Short-Form Health Survey), palliative care knowledge, and intention timing to withdraw dialysis (self-developed tool). ESRD patients with regular dialysis at a medical center and a clinic were recruited. Descriptive analysis and stepwise regression were conducted.

Results: One hundred and thirty-one patients were recruited with average 59.5 years old (SD±10.23) and seven years (SD±7.55) of dialysis. Majority were married (68%) male (58%) with no more than nine-year education (40%). Patients' preferred timing to withdraw dialysis was when the disease prognosis was less than six months. Dry mouth (mean: 5.02/10), itchy skin (mean: 4/10), and fatigue (mean: 3.79/10) were reported as top three symptom burdens. Majority of the patients (60%) possessed inadequate palliative care knowledge (mean 4.04/10). Physicians were identified as the key person to induce patients to think about dialysis withdrawal. Influential factors for dialysis withdrawal were patients' 1) educational level (B=0.633, t=2.117, p=0.031); 2) physical symptoms (Beta=0.234, t=1.879, p=0.036), and 3) palliative care knowledge (Beta=0.300, t=3.418, p=0.001).

Conclusions: ESRD patients' decision-making to withdraw dialysis is influenced by physician's suggestion, educational level, physical health status and understanding of palliative care, which should be considered while conducting advance care planning with them for goal-concordant care provision in the future.

Abstract ID: P02:16

Abstract type: Poster

Triggered Chain Reaction: The Meanings of Symptom Clusters for Patients With Chronic Obstructive Pulmonary Disease: A Cross-Sectional Qualitative Study

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Background/aims: To explore the experience of symptom clusters and their impacts on the health-related quality of life and symptom coping strategies of patients with chronic obstructive pulmonary disease (COPD). Patients with COPD experience multiple concurrent symptoms that have a detrimental impact on patients' health-related outcomes. To date, no studies have explored accounts of patients with COPD that

explore the meanings of they attribute to symptom clusters, their impact on their lives and how they cope.

Methods: Thirty patients were purposely selected from respiratory departments of three university teaching hospitals from November 2019 to April 2020. Semi-structured interviews were conducted and the data was analysed using the framework approach. Findings are reported following the COREQ checklist.

Results: Four main themes emerged: (i) experience of symptom clusters (i.e., typologies and interrelationships among symptoms, variations in concurrent symptoms); (ii) factors associated with symptom burden (i.e., physiologic, situational and psychologic factor); (iii) impact of symptom clusters on health-related quality of life (i.e., decreased physical functioning, social isolation, limitations in aesthetic needs and feelings of being stigmatized); and (iv) symptom coping strategies (i.e., mental-spiritual, self-management and medication control).

Conclusions: The early identification of COPD patients with symptom clusters and recognition of the central role that 'trigger symptom' play in experiences of multiple concurrent symptoms may provide insight into the future development of 'trigger-based' symptom cluster interventions. Nurses, therefore, need to assess symptoms on an ongoing basis, be aware of 'trigger' symptom and explore underlying mechanisms. The broad range of multifaceted impacts of symptom clusters on patients' quality of life identified in this study can help nurses develop holistic symptom management interventions.

Abstract ID: P02:18

Abstract type: Poster

A Qualitative Study of Experience of Patients Living With Chronic Obstructive Pulmonary Disease in the Primary Care Setting in Cape Town

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Background: Most deaths globally are attributable to non-communicable disease (NCD), and approximately 80% of deaths from NCDs occur in LMICs. In South Africa, the burden from NCDs is two to three times higher than developed countries with a high proportion of deaths from diseases of the respiratory system. Integration of palliative care into the care of people living with Chronic Obstructive Pulmonary Disease (COPD) can improve symptom management, psychosocial support and quality of life for these patients

Aim: The aim of the study was to describe views, experiences and needs of patients, family caregivers, and primary care health care professionals.

Methods: This was a qualitative study with a purposive sample of participants recruited for in-depth interviews. The study population was people living with CLD, their primary family caregivers, and health care professional at PHC facilities in Cape Town,. Interview guides were developed and interviews were conducted by trained research staff at the study sites. Data analysis: interviews were transcribed verbatim, translated into English, then imported into NVIVO version 12 for thematic analysis.

Results: We recruited 22 patients, 19 family caregivers and 22 HCPs from 5 primary health care facilities. We identified four main themes: Communication, Experience of patients and caregivers, Experience at healthcare facilities, Patient preferences and agency.

Conclusions: Preferences expressed were for improved communication, education on disease management and prognosis, support of symptom self-management, and community care support to improve continuity of care.

Individualised person-centred palliative care integrated into standard primary care has the potential for improved patient care and quality of life.

Abstract ID: P02:19

Abstract type: Poster

Participation of Elderly, Cognitively Impaired Cancer Patients in End-Of-Life Decision-Making: A Qualitative Study Using Non-participant Observation

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Background/aims: Decisions at the end-of-life (EOL) are complex and preference-sensitive. Treatment decision-making at the EOL is especially challenging for patients with comorbid cancer and cognitive impairments. This study aimed to examine patients' involvement and relatives' roles in EOL decision-making.

Methods: We conducted a qualitative study using non-participant observation of EOL decision-making in advanced cancer. A total of 12 medical consultations with 11 cognitively impaired patients in a German University Hospital were observed. Consultations were audio-recorded and transcribed verbatim. Data were analysed according to qualitative content analysis using MAXQDA 2018.

Results: In the beginning of the conversation a *base for participation* and a *framework for the decision-making situation* were created. Patients actively participated through *assertive responses, asking questions and expressing negative emotions*. Patients received support for participation by physicians through *clarifying the need for information, asking open questions, paraphrasing and re-involving the patient in the conversation*. Relatives supported the patient by giving *communicative support* as well as *informational support* and *helping to implement the decision*. Participants *co-constructed the patient's will* during the consultation. The process of co-construction was based on patient's utterances about *values, appraisals, preferences* as well as a *reconstruction of the patient's will by relatives*. The final decision was often made through a negotiation process considering the patient's and the relatives' perspectives and values.

Conclusions: Although elderly, cognitively impaired cancer patients actively participate in EOL decision-making, physicians and relatives play a crucial role in supporting patients in this process. Decision-making was often based on a relational understanding of autonomy and involved a complex balancing in order to ensure patients' autonomy while also taking into account relatives' needs and concerns.

Abstract ID: P02:20

Abstract type: Poster

National Multicentre Cross-Sectional Study to Identify Medical, Social and Ethical Problems of the Elderly Population in Georgia

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Background/aims: Identification of medical, social and ethical problems of the elderly population in Georgia.

Methods: National multicentre cross-sectional study was conducted in primary and home care settings from 2018-2020. Elderly patients (65+) with Montreal Cognitive Assessment score of 16 and more were included. Health care providers recorded medical information such as primary diagnosis, Karnofsky Performance Status (KPS), and specific information on depression, while patients registered socio-demographic information, subjective symptoms, Geriatric Depression Scale (GDS),

Activities of Daily Living (ADLs), and Instrumental Activities of Daily Living (IADLs). In addition, the patient had to answer semi-structured questions on living and health service preferences.

Results: 878 questionnaires were filled in 18 centers from different regions in Georgia. 74% of the patients were receiving primary care. Mean age was 75 years (SD 6.6), and mean KPS was 72 (SD 11.6). 71% of the patients were female, and 26% were living with children. Most of the patients (37%) experienced multiple co-morbidities. More than 63% had mild dementia. 71% of the patients experienced four or more different symptoms for the last two weeks. 37% of the patients had depression on GDS and 7% were receiving antidepressants. 16.5% and 39.3% of the patients scored negative on ADLs and IADLs, respectively. More than 75% preferred to live with their families. 72% mentioned that it is acceptable for elderly to live in nursing homes, if the patient is single or needs special care, however 46% preferred receiving primary care services.

Conclusions: This national multicentre study showed that elderly patients are experiencing multiple chronic co-morbidities in Georgia. Higher number of patients had symptom distress. Although majority of the patients mentioned that it is acceptable to live in nursing homes, they prefer to live at homes with relatives.

Abstract ID: P02:21

Abstract type: Poster

What Contributes to or Hampers Living at Home Until the End-Of-Life With Advanced Dementia? An Interview Study Among Family Caregivers, General Practitioners and Case Managers

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Background/aims: Although people with dementia often prefer to live at home until the end of life, they often die in a nursing home. The aim of our study was to obtain insight into circumstances that contribute to or hamper living at home until the end of life with advanced dementia.

Methods: Interviews with twelve cases were held with family caregivers, general practitioners (GPs) and case managers. We included cases in which persons with dementia lived at home until the end and cases that were admitted to a nursing home.

Results: The interviews indicate that family caregivers play a key role in living at home with dementia. Family caregivers stated that support from case managers and/or GPs and support from their social network are important to maintain care at home. Additionally, respite care and planned takeover of care contribute to family caregivers' resilience and thereby to living at home until the end. A safe living environment was mentioned as a pre-condition for living at home until the end of life. As the dementia progressed, in some cases safety issues, serious challenging behavior of the person with dementia and (as a consequence) an increased care burden changed the perspective of family caregivers on remaining at home until the end of life. This ultimately led to the decision to move the person with dementia to a nursing home.

Conclusions: This study underlined the importance of sufficient and timely support for family caregivers in caring for a person with advanced dementia living at home. Involving a case manager early in the care process can help monitoring the safety of the living situation, and monitoring family caregivers' resilience. We showed that timely and sufficient support and guidance, including clear communication with healthcare professionals on current and future situations and needs, is highly valued by family caregivers. It contributes to their perceived satisfaction with the care process, also in cases where nursing home admission of the person with dementia was inevitable.

Abstract ID: P02:22

Abstract type: Poster

Facilitated Online Video Interviewing with Older People with Advancing Frailty: A Novel Approach to Co-Production

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Background/aims: The voices of older people with advancing frailty (OPWF) are less often heard in research, made worse by the COVID-19 pandemic. In-person video interviews with this population about their care needs were adapted to a facilitated online video design. This paper assesses whether this design can support older people's participation in and co-production of research.

Methods: Video-recorded interviews (N=10) were undertaken October-November 2020 with multi-actor^(a-d) involvement, where a clinician^a facilitated interviews from the OPWF's^b home with the research team^c interviewing remotely via Zoom. Unpaid carers^d (N=5) sometimes supported interview participation. Ages ranged from 70-99, 6 men, 4 women, with no internet access (N=5) or family facilitated internet access (N=5), and Clinical Frailty Scores of 6 (N=5), 7 (N=4), or 8 (N=1).

Results: Multi-actor involvement led to less structured encounters than planned and more intuitive, co-produced, and situationally led interviews. Those interviewed felt that they had more opportunities to speak about things that were important to them, often expressing anger in feeling isolated and forgotten during the pandemic. The clinician described the benefit of the time given to the encounter, of the different conversations arising from a non- "routine" visit, and reflected on the different roles they held in supporting the participant by checking their understanding, helping to pace the interview, support silences, and provide emotional support following interviews.

Conclusions: Innovating research design during the pandemic to enhance older people's voices is challenging within normative expectations of funding and ethics bodies, yet, with less in-person research, presents opportunities to trial novel co-productive approaches to involve older people. This novel approach highlights challenges and opportunities for remotely co-producing research with OPWF, with high costs and skill-set requirements as barriers but rich data and open conversations as rewards.

Abstract ID: P02:23

Abstract type: Poster

Participation of Cognitively Impaired Cancer Patients in End-Of-Life Decision-Making – Barriers and Facilitators

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Background/aims: In an ageing population an increasing number of people is expected to suffer from cancer and cognitive impairment. This may lead to challenges in decision-making, especially at the end-of-life (EOL), with patients requiring support from physicians and their family. The aim of this study was to explore physicians' and caregivers' experiences in EOL decision-making with cognitively impaired cancer patients and to identify barriers and facilitators for patient participation.

Methods: Two focus group interviews with eleven physicians working with cancer patients were conducted. In addition, we led three semi-structured individual interviews with caregivers of cancer patients with cognitive impairment. Data were analysed using qualitative content analysis.

Results: Heterogeneous views emerged among participants regarding the way and degree of how cognitively impaired patients are involved in

EOL decision-making. Participants mentioned 'lack of resources', 'lack of advance planning' and 'communication problems' as barriers to patient participation. 'Taking time', 'multiprofessional collaboration' and 'addressing decisions early' were identified as facilitators to patients' involvement. Another helpful factor appears to be 'involvement of caregivers in the decision-making process', as they can give valuable information about the presumed patient's will. Further, they can act as a mediator between physicians and patient in order to reach a decision together. Caregivers' perception of how closely involved they were in the decision making process varied widely. All caregivers expressed a desire for more support to engage in and cope with the decision-making process.

Conclusions: EOL decision-making is a challenge for everyone involved in caring for cognitively impaired cancer patients, whether professionals or caregivers. For a successful participation it is essential that physicians invest time and communicate closely with caregivers.

Funding: This work was funded by the German Cancer Aid.

Abstract ID: P02:24

Abstract type: Poster

Needs and Problems of People With Dementia Living at Home: A Mixed Methods Study

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Background/aims: Policy in the Netherlands is aimed at keeping patients with dementia at home for as long as possible. Home care nurses have an important role in caring for patients with advanced dementia. The aim of this study was to gain insight in the main problems nurses experience in caring for patients with dementia at home; the symptoms and problems of these patients as registered in the electronic nursing file; and relatives' experience of symptoms and quality of life of patients with dementia living at home.

Methods: In a mixed method study, we performed 1. a survey among nurses from four home care organizations in the southwest of the Netherlands; 2. a study of nursing files of clients with dementia from 4 home care organizations on registered symptoms, nursing goals and activities; 3. a survey among relatives of patients with dementia living at home on their experience of symptoms, problems and quality of life.

Results: The main problems reported by nurses (n=83) caring for patients with dementia at home were waiting lists for admission to a nursing home (46%), transfer of information from the general practitioner (36%) and hospital (33%), and recognition of symptoms and problems (27%) and discussing these (17%). Most common symptoms reported in the electronic nursing files (n=92) were problems with eating and drinking (62%), fatigue (10%) and edema (9%). Relatives (n=15) most often reported fatigue (77%), confusion (47%), muscle tension (43%) and pain (36%). Relatives (n=15) reported an average score for quality of life of patients with dementia of 5,8 (scale 0-10).

Conclusions: Nurses report several problems in the care for patients with dementia at home including difficulties in the recognition of symptoms. Relatives report more and different symptoms, than nurses. Nurses' skills in identifying and managing symptoms of patients with dementia living at home may be improved.

Abstract ID: P02:25

Abstract type: Poster

A Feasibility Study of a Decision Aid to Support Family Carers of People with Dementia

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Background/aims: There are over 850,000 people with dementia in the UK and the majority of people with dementia live in the community, such as with family. Families provide the majority of care for people in the community. As dementia progresses and the person loses capacity, family carers may be left with difficult decisions about end of life care. Decision aids have been shown to help support decision making and may help clarify options about end of life care. We developed a decision aid to support family carers making decisions on behalf of the person with severe dementia or those towards the end of life. Our aim for this study is to test the acceptability and feasibility of the decision aid for family carers of people with severe dementia.

Methods: A feasibility study with a recruitment target of 30 family carers. The family carers all received a paper-based decision aid to be used whilst making decisions about end of life care. The primary outcome was regarding feasibility of the study. Quantitative outcome measures were completed at baseline, 3 and 6 months, including the Decisional Conflict scale (DCS) and Kessler Psychological Distress Scale (K10). Our success criteria for whether it was appropriate to progress to a full evaluation included: 70% recruitment rate of our target and a retention rate of 70% at 6 months.

Results: 26 family carers (87% of target) completed baseline assessment and 20 (77%) of those were followed-up at 6 months. Almost all quantitative outcomes changed in a direction indicating improvement over 6 months, including the DCS which decreased by 4.14 [95% CI (-0.52, 8.80)] showing less conflict regarding decisions at 6 months and the K10 decreased by 0.8 [95% CI (-1.52, 3.13)], showing a lower level of psychological distress.

Conclusions: Our study met our success criteria and showed it is feasible and acceptable to recruit family carers in a study exploring the decision aid. Future research should test the effectiveness of the decision aid in a fully powered trial.

Abstract ID: P02:26

Abstract type: Poster

Patterns of Deaths in People With Dementia and Alzheimer's During the COVID-19 Pandemic in England: Lessons for Palliative Care Before the Next Pandemic

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Background/aims: Older people had the highest death rates in England during the COVID-19 pandemic, before the vaccination programme. Deaths in care homes were especially high in the 1st Wave (W1) - April 2020 of the pandemic, with a lower peak in the 2nd Wave (W2) - December 2020/January 2021. People with Dementia and Alzheimer's (D&A) were among the most vulnerable to become victims to COVID-19.

Aims: To describe mortality patterns in people with (D&A) during the COVID-19 pandemic to learn lessons for Palliative and End of Life Care (P&EOLC) for D&A in pandemics.

Methods: Mortality data in England, January 2019 to May 2021 analysed by calendar month and place of death for D&A as underlying cause (UC) and contributory cause (CC) on death registrations. The key underlying causes for D&A CC deaths were identified. Comparisons were made for 2020 with 2019 and for W1 and W2 the same months in 2019/20 using descriptive statistics.

Results: In 2019, 64,468 people died with D&A as UC vs. 67,872 in 2020 (+5.3%), but strikingly deaths with D&A as CC increased 69% (26,445 to 44,624). The W1 and W2 peaks for D&A deaths were highly significant but different in nature. In W1 79% (8,435) D&A UC deaths were in care homes vs. 64% (3,435) 2019. For D&A CC deaths in W1 (April 2020) there was ~400% increase in deaths (2,146 to 10,682) and 325% and 569% increases in hospital and care home deaths. In W1 COVID-19 (7,496 deaths) was the main (70%) UC for

people dying with D&A as CC, increases also for Circulatory Disease +44%, Cancer +31%, Parkinsons +117% and respiratory disease (COPD) + 69.3%. W2 saw a 19% reduction in D&A UC deaths but +139% as CC with COVID-19 main UC.

Conclusions: People with D&A were extremely vulnerable to risk of death during the COVID-19 pandemic, especially if living in a care-home and due to pressures on healthcare. The speed of surge in deaths and impact on care homes highlights the critical need for Advance Care Plans/Power of Attorney for people with D&A and especially training of care home staff in P&EOLC.

Abstract ID: P02:27

Abstract type: Poster

Timely Short-Term Specialized Palliative Care For Older People With Frailty and Their Family in Primary Care: Easier Said Than Done

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Background/aims: Short-term specialized palliative home care that is initiated timely based on complex needs has been advocated for older people with frailty. But there is insufficient evidence on the feasibility of such an intervention.

To assess the feasibility and preliminary effectiveness of a timely short-term specialized palliative home care intervention (i.e., Frailty+) for older people with frailty and family.

Methods: Pilot randomised controlled trial and process evaluation. Eligible patients were 70 years or older, had a clinical frailty score 5–7, complex needs and about to be discharged home from hospital. They were randomly assigned (1:1) to Frailty+ or standard care. The Frailty+ group received specialized palliative care by a palliative home care nurse over 8 weeks, who followed guides for home visits. The primary endpoint was change on a sum score based on five key symptoms, i.e., breathlessness, pain, anxiety, constipation, drowsiness, over 8 weeks. Feasibility, implementation, mechanisms and context were assessed post-intervention using mixed methods. We used thematic and descriptive statistical analyses.

Results: 37 patients were randomly assigned to Frailty+ group (n=19, mean age 84y) or standard care (n=18, mean age 84y) and 26 family carers. The Frailty+ group received at least one home visit, as intended. Hospital care staff reported difficulties in patient identification. Patients and family reported positive views on the home visits, nurses that the guides were often not useful. Most important contextual factors were related to the COVID-19 crisis e.g., less continuity of care. Mean sum scores on primary outcome at baseline was 6.0 in Frailty+ and 5.6 in the control group, at 8-weeks was 4.5 in Frailty+ and 4.1 in the control group (adjusted ratio 1.0).

Conclusions: Frailty+ was well received by patients and family and to a lesser extent healthcare providers. Based on these results, further refinement of Frailty+ and RCT design is needed to optimize the intervention and evaluation.

Funding FWO

Abstract ID: P02:28

Abstract type: Poster

Preferences and Attitudes Towards Life-Sustaining Treatments of Older Chinese Patients and Their Family Caregivers

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Background/aims: Background: In mainland China, family involvement is crucial in older patients' medical decision-making at the end of life. It is unclear whether preferences and attitudes of family caregivers align with those of the older patients.

Aim: To compare preferences and attitudes of older Chinese patients concerning life-sustaining treatments with those of their family caregivers.

Methods: A cross-sectional survey was conducted in four communities in Zhengzhou. Dyads of older patients with chronic conditions and their family caregivers participated. The survey included questions about preferences for life-sustaining treatment, decision-making, timing, and motives.

Results: A total of 150 dyads completed the survey. The majority of older patients were negative about receiving CPR (86.7%), mechanical ventilation (70.6%) and chemotherapy (78%); positive about receiving artificial nutrition (67.3%); and had never considered hemodialysis (60.7%). Family caregivers were more often positive about the older patient receiving these life-sustaining treatments. Seventy percent of older patients were likely to have family caregivers make decisions on their behalf, with 44% of family caregivers preferring older patients to make their own decisions. Over half of family caregivers were likely to avoid the discussion until curative treatments were no longer effective, while most older patients preferred earlier discussion. The family burden is the major consideration for older patients when making decisions about medical treatment, while their family caregivers most value conscious experiences of older patients.

Conclusions: We conclude that family caregivers preferred more life-sustaining treatment than older patients preferred for themselves. Older patients' preferences about life-sustaining treatment should be accommodated in the decision making, including their preferences concerning the family's role, timing, and motives.

Abstract ID: P02:29

Abstract type: Poster

Hidden Patients With Dementia in Specialist Palliative Care?

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Background/aims: Dementia is incurable and classified as a life-limiting disease. The need for palliative care for people with dementia at the end of life is undisputed. Nevertheless, there is a lack of empirical data on their situation in a specialist palliative care context. How frequent is the documentation of a dementia diagnosis (main or side) among patients in specialist palliative care?

Methods: Analyses of documented diagnosis of dementia in an inpatient German university specialist palliative care department (ward and hospital palliative care team) and in a German specialist outpatient palliative home care service was carried out. Descriptive statistics were performed with Excel.

Results: Out of 7023 recorded patients admitted to the inpatient palliative care department between 2010 and 2020, 4599 were ≥65 years old. 157 (3.4%) were documented with dementia as main or side diagnosis. Out of 3621 patients using the outpatient specialist palliative home care service between 2009 and 2020, 2901 were ≥65 years old. 329 (11.3%) were documented with dementia as main or side diagnosis.

Conclusions: Compared to the prevalence in the public population of 8.6% in the group 65 years and older persons, patients with dementia are underrepresented in inpatient specialist palliative care. It remains unclear if dementia diagnoses are not recorded due to considered irrelevance in inpatient palliative care, or if patients with dementia lack access to inpatient palliative care delivery. Further research is urgently needed to make sure that persons with dementia receive adequate attention referring to palliative care needs, subsequent decision-making, and potential referral to palliative care services.

Abstract ID: P02:30

Abstract type: Poster

Influence of Dementia on Decision-Making for Elderly Cancer Patients at the End of Life

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Background/aims: There is an increasing number of elderly people suffering from comorbid cancer and dementia. In advanced disease stages, clinicians are facing the task of discussing medical treatment options with these patients. This study investigates how patients' dementia impacts clinicians' attitudes and preferences regarding decision-making in cancer care.

Methods: We randomly assigned N=50 clinicians involved in cancer care to two groups of an online survey. Using case vignettes describing patients with and without dementia, we assessed clinicians' desired degree of participation from patients and relatives. We evaluated their attitudes towards decisional control in triadic conversations and their preferences for value-based or reason-based decision-making.

Results: Comparing total scores from both groups, clinicians' preferred degree of participation from patients did not differ significantly. However, analysis of single items showed that information exchange and counseling on treatment options was considered less relevant by clinicians to whom the vignette of a patient with dementia has been presented. Accordingly, the importance of relatives' participation was rated significantly higher in this group. A shift of decisional control from patients to relatives could be confirmed using a visual model. While decision-making based on patients' values was equally important in both groups, a reason-based approach was considered less relevant in patients with dementia.

Conclusions: Dementia had no significant impact on clinicians' preferred overall degree of patient participation in decision-making. However, clinicians' desire for the involvement of relatives was increased. The comorbidity of dementia caused a significant shift of decisional control from cancer patients towards their relatives. Clinicians should be aware of relatives' influence and carefully weigh their level of involvement in decision-making processes near end-of-life.

Funding: This work was funded by the German Cancer Aid.

Abstract ID: P02:31

Abstract type: Poster

Co-designing the Process and Requirements to Use a Person-Centred Outcome Measure to Enhance Shared Decision-Making in Dementia Care

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Background/aims: Person-Centred outcome measures (PCOMs) have the potential to enhance shared decision-making and improve patient outcomes. However, little is known about the process and requirements

to use a PCOM to enhance shared decision-making with people living with dementia at home and family carers. This study aimed to co-design the process and requirements to use the Integrated Palliative Outcome Scale for Dementia (IPOS-Dem) and clinical decision resources to enhance shared decision-making with people living with dementia at home, family carers and care professionals.

Methods: Co-design workshops were held with family carers and health and social care professionals. Our systematic review informed the areas for discussion. After the first two workshops, a workflow diagram was developed to illustrate how the IPOS-Dem and clinical decision resource would enhance shared decision-making. Rapid thematic analysis of facilitator notes between workshops informed the following workshop.

Results: Three workshops were held, and the number of participants in each workshop ranged from 8-38. The key process for using the IPOS-Dem and clinical decision resources involves people with dementia and their family carer completing an assessment, discussing symptoms and concerns identified with a practitioner, discussing options for care and treatment, and agreeing on care goals, guided by clinical decision resources. Requirements for family carers to use the IPOS-Dem and clinical decision resources include short information and coaching sessions on the IPOS-Dem and clinical decision resources.

Conclusions: The next stage is to undertake a process evaluation and feasibility study for using the IPOS-Dem and clinical decision resources in routine care to enhance shared decision-making on care and treatment with people with dementia living at home, their family carers and care professionals.

Abstract ID: P02:32

Abstract type: Poster

Separated by a Common Language - Cognitive Interview Study on the Integrated Palliative Care Outcome Scale for People With Dementia (Ipos-Dem) in the Acute- And District Nurse/Community Care Setting *S. de Wolf-Linder^{1,2}, C. Ellis-Smith³, F. Hodiamont⁴, M. Reisinger¹, E. Gohles¹, F.E. Murtagh², M. Schubert¹*

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Background/aims: People with advanced dementia (PwD) are affected by symptoms and needs that are challenging for nurses and relatives to elicit. The UK-developed IPOS-Dem, translated/culturally adapted into Swiss-German for the acute care and community care setting, is a holistic, person-centred measure to aid caregivers to identify symptoms and needs. Comprehension of the IPOS-Dem needs to be tested before more detailed psychometric testing.

Methods: Nurses with diploma/university degrees and relatives over 18 years were purposively recruited. Rounds of a maximum three cognitive interviews were conducted. Thinking-aloud- and probing questions, based on Tourangeau's (comprehension, retrieval, judgement, and response) model, were applied with each participant. Interviews were transcribed and analysed from audio file by two independent researchers. Inconsistencies were resolved by consensus.

Results: Eight interviews in three rounds were completed in Spring 2021. Two relatives, three acute-care (ACNs), and three district nurses (DNs) agreed to participate. Participants welcomed the clear and understandable instructions, and description of all items. ACNs and DN differed in judgement of items, from being able to assess the PwDs need at all (e.g., feeling sad, enjoying things), to interpreting a symptom or need, and having different concepts in mind (e.g., agitation, wandering). Retrieval difficulties and

differences between ACNs and DNs were identified in psycho-social items (e.g., 'feeling at peace'); ACNs were reflecting on the PwDs overall life, whilst DNs were thinking about the present and how the PwD is affected by it.

Conclusions: The IPOS-Dem has been adapted in culture and content validity, with Swiss-German versions developed for both the acute care and community care setting. Although the versions do not differ substantially, the implications for teaching- and implementation of the IPOS-Dem into routine care diverge considerably.

Abstract ID: P02:34

Abstract type: Poster

Pre-Bereavement Experiences of Children with a Parent with Motor Neuron Disease: A Thematic Analysis

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Background/aims: Healthcare professionals and family members are often unsure of how best to support children pre-bereavement. Children who live with a parent with Motor Neuron Disease (MND) often also have carer responsibilities, and children classify as a vulnerable group and require extra support. Asking them about their experiences may help healthcare professionals better understand how best to support them.

Methods: Semi-structured interviews were conducted with three children aged 6 to 12 who have a parent with MND. The children were asked about what support they require or would like, how they obtain this support, and their interactions with healthcare professionals. The interviews were analysed qualitatively using thematic analysis, and the results were summarised narratively.

Results: Across the interviews four themes were identified:

- (1) perception of MND,
- (2) learning about MND,
- (3) emotional wellbeing and support, and
- (4) the role of a carer.

Children elicited both positive and negative aspects of living with a parent with MND. Having a parent with MND significantly affected their experience at home and at school. Even though the children did not self-identify as carers, they held significant carer responsibilities. Although they felt that MND was poorly understood by their classmates, the children found young carer groups beneficial, giving them an opportunity to relax and make friends. The children did not feel particularly well-supported by healthcare professionals and felt excluded from discussions around their parent's illness and treatment; they would have preferred to be more actively involved as part of the family.

Conclusions: The interviews provided invaluable insight into what support children would like from healthcare professionals and how best to improve communication with them. Actively involving children in the care of their parent and expanding and advertising resources for young carers is crucial in supporting children pre-bereavement.

Abstract ID: P02:35

Abstract type: Poster

Enabling Children and Young People to Take Patient and Public Involvement Roles in Paediatric Palliative Care Research

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Background/aims: Patient and public involvement (PPI) is essential to design and deliver meaningful research, but evidence on how to involve children and young people (CYP) in palliative care studies is limited. We aim to develop strategies to engage CYP PPI in paediatric palliative care (PPC) research.

Methods: CYP 10-21 years from an established UK PPI group provided feedback at three timepoints during a programme of research to develop and validate a PPC outcome measure. Virtual PPI sessions were held to gain input on measure content and design. The group were given a presentation introducing the team, the study and brief explanation of outcome measures. The task was explained, and the group split in two to complete it. Each group was facilitated by a researcher and PPI co-facilitator. Email involvement enabled co-development of participant information sheets. Feedback was given to the group on how their input had shaped the research via newsletters.

Results: 25 CYP attended the virtual sessions. CYP wanted to learn about the study and its importance. Giving choice in participating verbally, by virtual chat and email ensured maximum engagement. Facilitators provided everyone with the opportunity to participate. Feedback on sessions was positive. CYP enjoyed the opportunity to learn about new subjects - one blogged that the sessions were fun but important. Regular breaks and providing feedback on how the groups suggestions had been used were essential. The introductory presentation allowed the group to get to know the researchers prior to discussion.

Conclusions: CYP can be meaningfully involved in PPI roles within PPC research. We recommend giving a choice of ways to engage, including opportunities to learn about the study topic, allowing space to get to know the research team before completing tasks and giving feedback on how input has shaped the study. Having a facilitator known to the group also helped maximise involvement.

Funding: Funded by the European Research Council's Horizon 2020 programme [Grant ID:772635]

Abstract ID: P02:36

Abstract type: Poster

A Qualitative Study Into Parents' Experiences With Loss During Their Child's End-Of-Life: Enduring and Intrusions of Grief

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Background/aims: Parents of children receiving palliative care experience incremental losses and feelings of grief. During the end-of-life (EOL), the dynamics of being confronted with the growing threat of losing their child while fulfilling parenthood gets more strained. A better understanding of grief during the EOL will facilitate bereavement care aligned to the parents' needs. This study aims to gain insight into how parents experience and cope with losses and feelings of grief during their child's EOL.

Methods: An exploratory qualitative research design. Semi structured interviews were conducted with parents of children during the EOL or

shortly after death. Data were thematically analyzed in a multidisciplinary team.

Results: 37 parents of 21 children participated. During the EOL all parents were aware of the impending death of their child yet needed to emotionally keep grief at bay in order to endure. Four situations were identified that forced grief upon parents by confronting them with the threat of losing their child, and parents' active responses to cope with these threats. 1: Witnessing their child's suffering and decline, parents responded by being there and distancing themselves from the situation. 2: Losing grip on their child's situation, in response parents lived by the day, hold onto hope and positive thinking. 3: Being dependent on the health care professionals (HCPs) to ensure best care for their child, in response parents advocated for their child and sought a frame of reference. 4: (Non-)verbal interactions with HCPs, to which parents wanted to be available and find social support.

Conclusions: Healthy coping with grief is characterized by a dynamic process, yet the parents in this study were actively suppressing their grief to remain standing and were at times confronted with intrusions of grief. These insights are key in the provision of care where parents should be supported to remain standing to fulfill their parenting role. Emotionally loaded conversations should be well demarcated.

Abstract ID: P02:37

Abstract type: Poster

Challenges and Incentives for Integrating Person-Centred Outcome Measures Into Routine Paediatric Palliative Care: Health, Social Care and Commissioner Perspectives

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Background/aims: To successfully integrate a newly developed measure into clinical practice, the challenges and incentives for implementation must be understood, and these are specific to each measure. Previous research has focused on disease-specific measures, or the use of outcome measures in adult palliative care. Evidence is needed to ensure successful integration of new person-centred outcome measures (PCOMs) in the paediatric palliative care context.

Aim: To identify health and social care professionals (HSCP), and paediatric palliative care service commissioners' perspectives on the challenges and incentives to integrating PCOMs into routine paediatric palliative care practice.

Methods: Semi-structured interviews with purposively sampled HSCPs (caring for children <18 with life-limiting or life-threatening conditions) recruited from 9 UK sites; and commissioners of UK paediatric palliative care services recruited via a non-governmental organisation or direct recommendations. Verbatim transcripts were analysed using a framework approach and inductive coding in NVivo. 15 HSCPs and 12 commissioners were interviewed.

Results: Potential incentives for the use of a new PCOM included: (1) the measure helping HSCPs better understand what matters to children and families, (2) enabling better allocation of resources and services, and (3) enabling joined up working across teams and services. Potential challenges included: (1) gatekeeping by family members and (2) added workload for already stretched clinical services.

Conclusions: Understanding the perspectives of HSCPs and commissioners is essential for successfully integrating a new PCOM into paediatric healthcare practice. Identification of the potential challenges and incentives form the outset, with concomitant strategies for implementation, will help to ensure uptake into routine practice.

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Abstract ID: P02:38

Abstract type: Poster

Efficacy and Toxicity of Pediatric Palliative Radiotherapy: A Systematic Review

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Background/aims: Radiation therapy (RT) to relieve symptoms that significantly impact the quality of life remains infrequently utilized in pediatric patients with advanced or metastatic cancer. The lack of understanding about the utility and worrying over treatment-related side effects are the main obstructions to its diffusion. This systematic review aims to report data on the efficacy and toxicity of Pediatric Palliative Radiotherapy (PPR).

Methods: A SR based on PRISMA methodology was conducted. A database search on Pubmed of papers published from 1st January 2000 through 19th October 2021 was carried out. Only articles published in English were considered. Studies on RT combined with chemotherapy with single or multiple agents, new target agents therapies and/or surgery were included. Case series, editorials and reviews were excluded. The primary outcome was symptomatic response while the secondary end-points was toxicity.

Results: One hundred and forty-one papers were identified through Pubmed database searching. After the screening process, from 161 papers, only 10 met the inclusion criteria and were considered for this analysis. All studies were retrospective. The total number of included patients was 1.152. In all studies the median patients age was < 18 years (range 6.0-17.9). The most frequent indication was pain reported in percentage ranging from 20 to 80%, followed by dyspnea and neurological symptoms. Eight out of 10 papers reported on symptoms relieve with percentage ranging between 86% and 44% with a mean value of 68.4%. Two out of 10 paper did not report toxicity. Eight studies reported toxicity outcomes of whom five reported toxicities ≥ Gr.3 with percentage ranging between 0.3% and 6.7% (the highest percentage, were described in patients receiving concurrent chemotherapy and/or re-irradiation).

Conclusions: This review confirms that PPR is an important option to relieve symptoms. A recognition of its role in pediatric palliative care models is desirable.

Abstract ID: P02:39**Abstract type: Poster**

From Pediatric to Adult Palliative Care Service: The Continuity of Care
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Background/aims: Define a gradual transition from pediatric to adult palliative care able to support adolescent patients (pts) with chronic and progressive diseases and their family.

Methods: Since the pediatric pts followed by pediatric palliative care turned 16 years, they started to be followed simultaneously from the pediatric and adult palliative care team to guarantee the continuity care of pts and their family from a holistic point of view (physical, psychological, spiritual, social) during adolescence. It has been defined a multi-professional team constituted by pediatric and adult palliative care specialist, family doctor, nurses and psychologists specialized in palliative care, social workers and the referring hospital and territorial specialists.

Results: Our Pediatric Palliative Care (PPC) Team is a territorial service and works in the home setting in synergy with Hospital and Hospice. Our PPC team is following 170 patients 88 male (51,7 %) and 82 female (48,3%) with median age of 6 years (range 0-18). Pts's diseases were reported according to Royal College Classification: class I included 16 pts (9,4%); class II 5 pts (3%); class III 111 pts (65,3%); class IV 38 pts (22,3%). Out of 170 pts, 21 were > 15 years (14 male and 7 female), with a median age 16 years (range 15-18). In accordance with the Royal College Classification the pts were classified as follows: 1 pt in class I (4,8%); 2 pts in class II (9,5%); 11 pts in class III (52,4%); 7 pts in class IV (33,3%). Focusing on this group 18 pts (85%) had high or moderate clinical care complexity according to ACCAPED scale. The simultaneous presence of pediatric and adult palliative care specialists during each visit in different settings (ambulatory or home setting) and the participation in the review of Personalized Care and Support Planning was defined for a period 2 years, starting at the age of 16 until the age of 18 of the patients.

Conclusions: Through the integration of pediatric and adult services continuity of care is possible

Abstract ID: P02:41**Abstract type: Poster**

The Role of Acculturation in Chinese Immigrants' Engagement With Advance Care Planning: A Narrative Systematic Review

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Background/aims: Background: Chinese immigrants are in a process of acculturation, i.e., adapting to the prevailing culture of their host society and holding onto Chinese cultural values and traditions. It is unclear whether and how acculturation affects Chinese immigrants' engagement with advance care planning.

Aims: To synthesize evidence regarding the impact of Chinese immigrants' acculturation on their engagement with advance care planning.

Methods: EMBASE, MEDLINE, Web of Science, and Google Scholar were searched for publications until January 21, 2021. We included empirical studies on Chinese immigrants' engagement in advance care planning and their acculturation. Dual coding and thematic content analysis were performed on qualitative studies, and narrative synthesis and stepwise thematic analysis were conducted on quantitative studies.

Results: Twenty-two of 1,109 articles were included in the analysis; 18 had a qualitative design, 14 originated from the United States. Three of four quantitative studies reported that higher acculturation levels were associated with better knowledge of or higher willingness to engage with advance care planning. The qualitative findings showed that Chinese immigrants' engagement was influenced by their: (1) self-perceived identity (i.e., native or non-native); (2) interpretation of filial piety (i.e., traditional or modern); and (3) interpretation of autonomy (i.e., individual or relational). To facilitate their engagement, they preferred: (1) an indirect approach; (2) initiation by non-family members; (3) contextualization into Chinese philosophy; and (4) the use of Chinese terms and/or language.

Conclusions: We found that more acculturated Chinese immigrants were more willing to engage with advance care planning. An individualized approach to advance care planning should consider one's interpretation of self-identity, filial piety, and autonomy.

Abstract ID: P02:42**Abstract type: Poster**

Palliative Care Access for People in the UK Who Are Experiencing Homelessness and Who Have No Recourse to Public Funds

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Background/aims: People experiencing homelessness rarely access palliative care. Options for place of care are extremely limited meaning many people with poor health living in homeless hostels remained there when approaching the end of life. Hostel staff play a key role in advocating for access to care. Our previous research has focused on the experiences of people residing in homeless hostels but there is very little evidence regarding the experiences and access to palliative care for people who are homelessness and have no recourse to public funds, meaning that they cannot stay in homeless hostels or receive some NHS care. People with unsettled immigration status might face additional barriers to palliative care access due to complicated legal situations, societal stigma, limited support networks and inexperience navigating UK systems and services.

This research aims to explore the experiences of people with advanced ill health who are experiencing homelessness and have no recourse to public funds, and those that support from.

Methods: This project has three parts; a survey for hospice staff, focus groups with inclusion health staff and Interviews with people experiencing homelessness who have no recourse to public funds. Qualitative data will be analysed using thematic analysis with triangulation to explore different perspectives and experiences of the three groups and generate recommendations for improving support for this group.

Results: This research will provide new insights into an under-researched group. Challenges that are specific to this group and challenges that health and social care staff face in providing support will be explored and considered.

Conclusions: Understanding the experiences of people with no recourse to public funds, who are experiencing homelessness and whose health is poor, and those of the people that support them represents a crucial first step in ensuring that inequities in access to care for this group are recognised and acted upon.

Abstract ID: P02:43

Abstract type: Poster

Identifying Frailty and Holistic Health Issues Amongst People Experiencing Homelessness: A Pilot Study in Two Hostels

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Background/aims: People experiencing homelessness (PEH) often have complex health and support needs, and are often primarily supported by non-clinical hostel staff. Extreme levels of multimorbidity, premature onset of frailty and geriatric conditions at a young age have been observed in this population. Accessing adequate health and social care support, including palliative care support for PEH is challenging and non clinical staff supporting them struggle to advocate successfully for care for their clients. This study aimed to develop and pilot a questionnaire in collaboration with staff in homeless hostels and other experts working in the field of inclusion health to screen for frailty and other health and social care needs among PEH residing in hostels.

Methods: Through a consultation process with hostel staff and other inclusion health experts we developed the Frailty and Holistic Needs Questionnaire which incorporated an adapted Edmonton Frail Scale. The questionnaire was piloted in two hostels, with PEH completing the questionnaires with their keyworkers. Following the pilot, staff focus groups explored the acceptability of the tool to identify frailty and other issues, and its potential usage to advocate for support where needs were identified.

Results: 70 PEH completed the tool with their keyworkers. Over half (54%) of responding PEH were identified as having frailty and a further 21% scored for pre-frailty (vulnerability). Multiple other health issues were also reported. The questionnaire was viewed positively by staff and PEH and its completion stimulated productive conversations about participants' health priorities.

Conclusions: The tool was a feasible intervention to screen for frailty and other health and social care needs among residents of homeless hostels. This intervention has great potential for gathering evidence about health and social care needs to advocate for better access to care for a population that historically struggle to access it.

Abstract ID: P02:44

Abstract type: Poster

Evaluating a Three-Faceted Intervention to Improve Palliative Care For Persons Experiencing Homelessness : A Mixed-Method Evaluation on Process and Added Value

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Background/aims: Palliative care for persons experiencing homelessness is often provided late or not at all. A three-faceted consultation service was expected to increase knowledge of and collaboration

between professionals, and improve palliative care for this population. This service included 1) consultations between shelter staff and professionals in palliative care, 2) multidisciplinary meetings of these professionals, and 3) training and education of professionals. We aimed to evaluate this service implemented in three Dutch regions looking at the process of implementation and added value of the service.

Methods: A mixed-method evaluation study using structured questionnaires, semi-structured (group) interviews, and an implementation diary. RE-AIM framework and CFIR-constructs were used to identify barriers and facilitators of the implementation process.

Results: 34 consultations, 22 multidisciplinary meetings and 9 trainings were registered during the implementation period (September 2019 to June 2021). Mainly shelter staff were reached by the service. A need for improvement and an existing network facilitated adoption of the service, while limited skills of professionals hindered it. Implementation was facilitated among others by expertise of the consultant, and hindered by COVID-19 circumstances, staff shortages and lack of knowledge of palliative care. Embedding the service in regular, funded, meetings facilitated maintenance, while a small number of involved persons in this small-scale service hindered it. Added value was found mainly on supporting and connecting professionals, increasing their knowledge and practices, and improving quality of palliative care.

Conclusions: Implementing a three-faceted consultation service requires time, effort, and a perceived need among professionals. Once established, the intervention can help professionals in connecting professionals of two disciplines, to identify palliative care needs, and to provide timely and better quality palliative care to homeless persons.

Abstract ID: P02:45

Abstract type: Poster

IPOS-Dem: Language Matters to Involve Family Members

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Background/aims: The Integrated Palliative Outcome Scale for people with dementia (IPOS-Dem) has been developed for routine outcome evaluation of people with dementia's needs and concerns. IPOS-Dem is a brief and holistic assessment instrument for proxy assessment. In order to allow for proxy assessment through frontline staff in nursing homes and family members, IPOS-Dem was adapted to an easy language version. We translated and adapted IPOS-Dem during the IPOS-Dem Project from August 2020 to March 2021 in Swiss nursing homes.

Methods: We adhered to a six-step process to adapt IPOS-Dem for the Swiss context. Firstly, we undertook a review of current local practices. Secondly and thirdly, the German version of IPOS-Dem was forward- and backward translated. The resulting documents were reviewed and discussed by an expert committee (n = 9). We debriefed the pre-final version in two focus groups (n = 10). In phase six, we submitted the pre-final easy language IPOS-Dem, and reports of every phase to the pos-pal group for review and proof-read.

Results: Our review showed that current scales and instruments in clinical practice communicate in a complex and involved language. Phase two and three resulted in a thorough rework of IPOS-Dem properties. Experts facilitated the translation for easy language translation. Expert reviews and cognitive interviews concluded with good agreement.

Conclusions: The Instrument was adapted to allow for proxy assessment with three target groups: care staff without formal nursing training, family members, and registered nurses. Special attention was paid to allow for downstream use of IPOS-Dem outside of the nursing home setting. Our clinical partners in the IPOS-Dem project confirmed the relevance and

importance of routine outcome assessment for care quality and caring quality. The inclusion of family members in a structured way in the nursing process was particularly highlighted. However, further psychometric testing of the adapted IPOS-Dem is indicated and underway.

Abstract ID: P02:46

Abstract type: Poster

Supporting Family Caregivers of Patients With Life-Threatening Diseases: A Mixed-Methods Study Among Healthcare Providers, Part of the Support for Family Caregivers Projects, 2017-2024

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Background/aims: Support for family caregivers is an essential component of palliative care. We aimed to assess practice of supporting family caregivers of patients with life-threatening diseases, and facilitators and barriers to supporting family caregivers as perceived by healthcare providers.

Methods: A survey exploring healthcare providers' practice of supporting family caregivers in Western urbanized Netherlands in 2017. The results informed the interview guide that was used in four focus group interviews with 22 healthcare providers conducted in 2018. The focus group data were analyzed thematically, and deductively with the COM-B system, which suggests that people need capability (C), opportunity (O) and motivation (M) to perform a behavior (B).

Results: Of the 379 healthcare providers (response 11.1%) who completed the survey, 375 were eligible (physicians, 27.4%; nurses, 63.7%; nurse aides, 8.5%). Respondents worked in academic hospitals (52.5%), general hospitals (31.2%), nursing homes (10.7%) or hospices (5.6%). Respondents reported to always (37.1%), most of the time (37.1%), or sometimes (20.5%) provide support to family caregivers. Few (4.7%) reported to never do so. The respondents reported to always (28.0%), sometimes (39.2%), or never (32.8%) provide support to bereaved family caregivers. The focus group data indicated motivational facilitators and barriers to supporting family caregivers (e.g., relationship with family caregivers, deriving satisfaction from supporting family caregivers), and factors related to capability (e.g., conversational skills, knowledge) and opportunity (e.g., available protocols and time).

Conclusions: Support for family caregivers is not systematically embedded in healthcare institutions in an urbanized region in the Netherlands. The barriers and facilitators identified in this study, such as motivation and available protocols, can aid the development of a behavior change strategy for healthcare providers to enhance the practice of systematic support for family caregivers.

Abstract ID: P02:48

Abstract type: Poster

Providing Family Care to Older People Living With Frailty: Learnings From the Experiences of Dual Experts

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Background/aims: Older people living with frailty are vulnerable to sudden and fluctuating deterioration. Family carers need to be supported to recognise the signs of these deteriorations, to know who to contact and

what language to use to engage relevant care services. Family carers who have been health professionals (known here as 'dual experts') can provide unique perspectives on identification and response to signs of deterioration in an older relative, from their dual professional and personal caring roles. This paper aims to understand dual experts' experiences and responses to the deteriorations of a relative living with frailty.

Methods: A qualitative research design over 4 months. Stage 1: One-to-one interviews with dual experts (N=6). Stage 2: Focus group with the same interview participants (N=5).

Results: The focus groups identified values and skills seen as important for providing family care: 4 carer-oriented (Resilience; Pacing Yourself; Awareness of Own Needs; and Wanting to Be There) and 4 relative-oriented (Discreet Vigilance; Sensitive Positivity; Clear Communication; and Supporting Autonomy). Thematic analysis identified 4 proactive approaches to family caring (Preparation; Coordination; Relationship Building; and Responsiveness to Change). Rather than a standard set of responses, dual experts described their reliance on creative or imaginative solutions to deal with problems in the moment, rather than address them in advance.

Conclusions: Values and skills were often discussed in relation to challenges dual experts experienced in their caregiving, thereby revealing important areas where family carers could receive training and support. Dual experts' accounts emphasised planning and local network building to ensure support structures and care are in place, as well as responsiveness to creatively adapt when deterioration occurs. Responses often drew on clinical knowledge and skillsets and these findings require testing with non-dual experts to assess how they may translate to carers more widely.

Abstract ID: P02:49

Abstract type: Poster

"A Dual Challenge": Palliative and Hospice Care Providers' Perceptions on the Dual Role of Family Caregivers

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Background/aims: Family caregivers (FCs) of terminally ill patients combine the roles of being a caregiver and a person in need of care. However, we have little understanding on what it means for FCs to live with this dual role. Aim of our study was to explore the dual role experience of FCs from the perspectives of palliative and hospice care providers.

Methods: Qualitative explorative focus group study, using grounded theory (coding paradigm). Ten multi-institutional focus groups were conducted with multidisciplinary teams from palliative care and hospice services (n=64).

Results: The healthcare providers voiced that FCs, consciously and unconsciously, struggle with their dual role while striving for being the best FC. Strategies of FCs to deal with their struggle include *Affirming caregiving as gift-giving; Trying to keep one role intact; Living with ambivalence; Seeking for absolution from the outside; Getting in touch with other FCs; Learning to ask for help.* Several conditions may affect FCs' struggling with the dual role as well as the strategies they use. These include the societal neglect of FCs' neediness, attitudes from family and friends, FCs' moral distress, FCs ability to self reflect, and availability of support. A feasible outcome is that FCs recognize and honor both roles and embrace the duality of the caregiving role to the fullest. However, FCs tend not to self-identify as persons in need of care and regularly overlook their needs and well-being, while self-identification with the role of being a caregiver is nuanced. Ultimately, FCs struggle includes an involuntary waiting for the patient's death when caregiving ends, and this waiting can cause tension, confusion and feelings of guilt in FCs.

Conclusions: The study shows the complexity of FCs' struggling with their dual role that is implied in caring for a loved one. Results can

increase healthcare providers' awareness of this struggle and generate insight into how to support FCs in coping with their dual role.

Abstract ID: P02:50

Abstract type: Poster

Music Therapy for Supporting Informal Carers of Individuals With Life-Threatening Illness Pre- And Post-bereavement; A Mixed-Methods Systematic Review

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Background/aims: Music therapy intervention with informal carers of individuals with life-threatening illness at pre- and post-bereavement is an increasingly important clinical area for music therapists. There is, however, uncertainty about music therapy's effectiveness in this context, the mechanisms through which music therapy may influence outcomes, and how music therapy is experienced by adult informal carers. This systematic review is the first to synthesise and critically evaluate the current state of the evidence-base for music therapy intervention with adult informal carers of individuals with life-threatening illness at pre- and post-bereavement. The objectives of this review are to describe the characteristics, effectiveness and experience of music therapy intervention which aims to improve health-related outcomes addressing whole person health for adult informal carers (pre- and post-bereavement).

Methods: The Joanna Briggs Institute methodology for mixed-method segregated systematic reviews was followed. Six databases were searched; MEDLINE, EMBASE, PsycINFO, RILM Abstracts of Music Literature, CENTRAL and CINAHL, from 1998 to the current year. Reference and citation harvesting was undertaken, in addition to a contacting experts phase.

Results: 32 studies were included. Currently the studies are being critically appraised using JBI critical appraisal tools. Both qualitative and quantitative data will be extracted using JBI tools for mixed-methods systematic reviews. A convergent segregated approach to synthesis and integration will be used. The findings of the synthesis will be configured according to JBI methodology and presented.

Conclusions: Although music therapy with adult informal carers of individuals at end-of-life is an emergent clinical area, evidence for music therapy intervention in this context is thought to be limited. The findings of this review will inform evidence-based practice and future research.

Abstract ID: P02:51

Abstract type: Poster

What Defines High Quality Care? Parental Perspectives on Key Services and Behaviors Delivered by Health Care Providers of Seriously Ill Young Children

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Background/aims: A popular axiom in business is that 'you can't improve what you don't measure.' Despite efforts by the Ministry of Health and local health systems to measure the quality of curative treatments for serious illnesses, few efforts have focused on systematically understanding how well care is delivered, much less for the pediatric population. This is largely because no prior local study has elicited what are the key services and behaviors delivered by health care providers (HCPs) that are key for experiential assessment, inhibiting the development of experience indicators. This inductive grounded theory study used a social

constructivist lens to develop one of the first parent-driven framework of key services and behaviors delivered by HCPs.

Methods: 32 parents from different families with a young child (<8 years) living with a serious illness participated in either in-depth interviews or focus group discussions to enable data source triangulation. Parents were recruited from multiple service delivery settings as children with serious illnesses receive services from multiple bodies or institutions both simultaneously and over the course of their disease. Evaluation should cover all HCPs involved in a child's network of care providers to provide a comprehensive evaluation of parent's experiences. Thematic analysis using constant comparative analysis was carried out.

Results: Preliminary themes identified are: 1) Ensuring accessible medical care, 2) Providing competent medical care, 3) Coordination of care, 4) Effective and comprehensive communication, 5) Empowering and supporting parents as caregivers at home, 6) Providing family-centered care, 7) Providing and facilitating psychosocial support to parents, 8) Reducing parental stress and caregiving burdens and 9) Providing holistic care for the child.

Conclusions: The framework will optimize modification of parent reported experience measures which can be used to quantify and measurably improve the care experience.

Abstract ID: P02:52

Abstract type: Poster

Relatives of Patients With Life-Threatening Organ Failure: The Impact of Caring

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Background/aims: Relatives are frequently involved in the care of patients with life-threatening illnesses, which may have implications for their quality of life/health. Aim was to analyze caregiver burden, dyadic coping and health-related quality of life in relatives of adult patients with renal failure (RF), cystic fibrosis (CF), and intestinal failure (IF).

Methods: Three cross-sectional studies for each patient group were conducted (2019-2020). Patients were asked to indicate the closest relative. Self-report instruments: Zarit Burden Interview (ZBI, total score ≥ 17 =greater burden), Dyadic Coping Inventory (DCI subscales: stress communicated by oneself, max score 20; stress communication of the patient, max score 20; common dyadic coping, max score 25, and evaluation of dyadic coping, max score 10; higher score=better result), and 36-Item Short Form Survey (SF-36, max score 100, higher score=better result). Chi-square and Wilcoxon tests. Significance level: $P < 0.01$.

Results: Relatives numbers: RF=78, CF=104, IF=73. Groups' mean age 46-60y. The groups differed regarding sociodemographics; however, majority in all groups was female (56-80%), cohabitant partner (50-78%),

work active (56-89%), and had upper secondary/vocational or higher education (>80%). ZBI: similar total score ≤ 14.3 ; groups differed for cleaning/other tasks hours (RF: 4.7 ± 6.0 , CF: 4.0 ± 13.4 , IF: 5.0 ± 5.3 , $P=0.008$) and personal care hours (RF: 0.5 ± 1.8 , CF: 0.2 ± 1.6 , IF: 0.3 ± 1.0 , $P=0.009$). DCI: lowest mean scores for stress communicated by oneself (9.7 ± 3.5 - 11.3 ± 3.5) and by patient (11.0 ± 3.1 - 12.2 ± 3.9); no group differences. SF-36: lowest scores for fatigue and general health (52.8 ± 15.8 - 60.8 ± 22.1); group differed regarding role functioning/physical (RF: 76.3 ± 35.1 , CF: 90.3 ± 26.3 , IF: 74.6 ± 39.3 , $P=0.002$).

Conclusions: The groups of relatives shared common areas of issue related to the hours of care, stress communication between patient and relative, fatigue and condition of general health, which deserve attention.

Study supported by Region Hovedstaden.

Abstract ID: P02:53

Abstract type: Poster

What Matters to Users? - Evaluation of the Look and Feel and Content of a Family Booklet on Comfort Care in Advanced Dementia: A Mixed-Methods Study Assessing Users' Preferences

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Background/aims: Background: A Canadian booklet on comfort care for caregivers of people with advanced dementia that was issued in 2005 has been translated and adapted for use in a number of countries including the Netherlands. Evaluation studies have focused mainly on revision of its content, whereas in the meanwhile, a variety of formats to provide information are in use in healthcare such as web-based products.

Aim: To evaluate the preferred look and feel and content of the comfort care booklet among family caregivers and healthcare professionals.

Methods: In this mixed-methods study, family caregivers of people with dementia and professionals evaluated the current Dutch booklet. To visualize potential features and options for revision, two prototypes and three sets of illustrations were embedded in a digital questionnaire with closed and open-ended items.

Results: Twenty-one family caregivers and 19 professionals completed the questionnaire. Caregivers expressed a need for the information booklet, some suggested to provide it early. The booklet's current look and feel received positive evaluations due to its table of contents, ease of use, and ease of access for caregivers. However, it should include more diverse and less medical images. The booklet format was preferred the most by the caregivers (52%), and could be supplemented by a digital format. Both caregivers and professionals wished a focus on patient/caregivers' well-being and communication rather than largely limited to medical aspects of late-stage dementia.

Conclusions: This study allows for adapting the booklet to the preferences of end-users to support optimal use. This could bridge a gap between created final products based on researchers' knowledge of medical aspects and end-users' preferences.

Abstract ID: P02:54

Abstract type: Poster

Narrowing the Frame to Manage Distress in Family Caregivers of Patients with Acute Leukemia: A Grounded Theory Study

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Background/aims: The diagnosis, progression, or recurrence of life-threatening or advanced cancer is often highly traumatic for family caregivers (FCs). Acute leukemia (AL) is prototypical for the acute onset of a life-threatening disease, with intensive treatment and severe physical symptoms. Post-traumatic stress disorders occur in a substantial proportion of FCs of patients with AL, but there is a scarcity of research to elucidate their experience. We aim to characterize the experience of FCs in the first month after the diagnosis of AL in their family member.

Methods: FCs of patients with AL (N=9) were recruited to participate in a qualitative interview about their experience with AL in the first month after diagnosis. A grounded theory approach was used to analyze interviews.

Results: Preliminary data identified three phases in FC distress: anticipatory, acute, and post-acute. The anticipatory phase, which precedes diagnosis, was characterized by a gradual increase in distress fuelled by concerns related to uncertainty. In the acute phase, which occurs after diagnosis, we observed an unexpected decrease in distress. Further analyses showed a delicate balance between five stressors that heightened distress in FCs (helplessness, fear of a bad outcome, patient's state, continuous traumatic events, and juggling two worlds) and the internal adaptive mechanism activated in response to this distress. This mechanism termed "narrowing the frame" occurred on cognitive, emotional, and behavioural levels. FCs made subconscious and intentional efforts to remain present-oriented, avoid/dissociate from negative thoughts/emotions, and focus on actionable tasks.

Conclusions: The investigation and diagnosis of AL is typically followed by overwhelming distress. In the acute phase, FCs "narrow the frame" to decrease this emotional intensity. Efforts by researchers to "widen the frame" at this time resulted in resistance from FCs, which is relevant for the development of targeted psychotherapeutic interventions for this population.

Abstract ID: P02:55

Abstract type: Poster

Cases With Cancer and Amyotrophic Lateral Sclerosis Comorbidity Featured in the Japanese Literature Over the Past 10 Years

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Background/aims: Amyotrophic lateral sclerosis (ALS) has no established treatment. However, long-term survival is possible with symptomatic management including tracheostomy positive pressure ventilation. In contrast, there are various treatments for cancer. The issue of comorbidity has been recognized largely in an aged society. The aim of this study was to conduct a literature review regarding patients with both ALS and cancer, to find better care for them.

Methods: We searched the literature from 2010 to 2021 using the Japan Central Revuo Medicina Web (ver. 5) electronic database, with a combination of the following keywords: amyotrophic lateral sclerosis and cancer. We extracted 124 articles and 20 met the selection criteria: 16 reports were from physicians, 3 from nurses and one from a pharmacologist. All 20 articles were case reports; 19 dealt with single cases and one with four cases, making a total of 23 cases, which were analyzed in detail.

Results: In our analysis of 23 cases, 13 (57%) of the patients were in their 70s or over; 16 (70%) cases were diagnosed with ALS before cancer, 2 (9%) with cancer first, and 5 (21%) with both at about the same time. The most common type of cancer was colorectal cancer (8 cases) followed by lung cancer (4 cases) and pancreatic cancer (3 cases). The literature included 14 cases related to surgery or anesthesia for surgery, 5 cases related to either chemotherapy or radiotherapy, and 5 cases with

no cancer treatments. In all but three reports of ALS patients treated for cancer, the cancer treatments were described as successful. The reports on postoperative nutritional management and pain relief were also successful cases.

Conclusions: An interdisciplinary and comprehensive review is necessary to provide the optimum course of treatment. There is no need for patients suffering from ALS to give up cancer treatment. The results of this study could help improve support for those patients in terms of deciding the best medical treatment or facilitating advance care planning.

Abstract ID: P02:56

Abstract type: Poster

Intramedullary Spinal Cord Metastasis (ISCM) An Unusual Cause of Back Pain and Management Challenge

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Background/aims: A 36-year-old woman with known metastatic breast carcinoma with numerous intracranial, liver and diffuse osseous metastases developed new shoulder and intrascapular pain during an inpatient hospice admission

Methods: Neurological examination demonstrated established cerebellar signs with no new features suggestive of spinal cord pathology.

A sagittal T2 weighted MRI of the whole spine demonstrated a new intramedullary metastatic deposit in the upper thoracic cord at the level of T1 with associated syringohydromyelia. The MRI further demonstrated interval progression of the known osseous metastatic disease.

Results: Due to the patients underlying frailty and ECOG of 3, consensus of the treating team was that the patient would not be suitable for neurosurgical intervention. Radiation oncology colleagues recommended high dose corticosteroids and palliative radiotherapy to the thoracic lesion. The patient had previously poorly tolerated high dose corticosteroids, which were commenced for symptoms secondary to extensive intracranial metastatic disease and subsequent mass effect, developing an elevated mood and irritability. This was felt to be likely on the background of cognitive impairment secondary to extensive brain disease. Her subsequent emotional lability and anxiety led to significant distress necessitating down-titration of the corticosteroids and commencement of an anti-psychotic. Following extensive multi-disciplinary team discussions, best supportive care was felt to be the most appropriate management in this case.

Conclusions: The incidence of ISCM is expected to increase with improved imaging modalities and is associated with significant neurological deterioration. Fractionated radiotherapy usually maintains pre-treatment neurological function. ISCM should be considered in the differential diagnosis for thoracic back pain in patients advanced cancer, especially in patients with cerebral metastases, as one third of patients with an ISCM have concurrent cerebral metastases.

Abstract ID: P02:57

Abstract type: Poster

“Empty and Lost”: The Challenges of Being Bereaved During the COVID-19 Pandemic

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Background/aims: The COVID-19 pandemic has resulted in millions of deaths worldwide, whilst also causing severe disruption to end-of-life, grieving and coping processes. We examine bereavement experiences during the pandemic and relate our findings to the constructs of loss-oriented and restoration-oriented coping, described in Stroebe and Schut's Dual Process Model (DPM).

Methods: Two independent UK-wide surveys were disseminated online, including via social media and community/charitable organizations. They captured adult experiences of bereavement (to all causes of death) from March 2020 to January 2021. Free-text data were analyzed thematically.

Results: Free-text comments were provided by 881 participants. Six main themes were identified: troubled and traumatic deaths; disrupted mourning, memorialization and death administration; mass bereavement, media/societal responses and the ongoing threat of the virus; grieving and coping (alone and with others); workplace and employment difficulties; and accessing support via health and social care. Examples of loss-oriented stressors included being unable to visit or say goodbye, the sudden and traumatic nature of many deaths, and restricted funeral and memorialization practices. Reactions included feelings of guilt and anger, and problems accepting the death and starting to grieve. Examples of restoration-oriented stressors and reactions comprised stressful death-related administration and severely curtailed social networks, support systems and social/recreational activities, which impacted peoples' ability to cope.

Conclusions: These results demonstrate the exceptionally difficult sets of experiences associated with pandemic bereavement, defined by significant disruption to end of life, death and mourning practices, as well as usual coping mechanisms and formal or informal bereavement support. The DPM provides a useful framework for conceptualizing the additional challenges associated with pandemic bereavement and their impact on grieving and mental health.

Abstract ID: P02:58

Abstract type: Poster

Experiences of Bereavement Across the UK, What Are the Challenges and What Might the Future Look Like – Findings From the UK Commission on Bereavement

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Background/aims: The increased number of deaths due to the COVID-19 pandemic has left many people bereaved. Working in partnership with a number of UK charities and researchers, the UK Bereavement Commission was established to ensure that the voices of those affected by bereavement are heard and considered in future services and supports for bereaved people across the UK.

Aims: To explore experiences of people bereaved in the last 5 years and identify recommendations for policy and practice with the aim of improving the experiences of people affected by bereavement.

Methods: Two online surveys were launched in September 2021, one collected individuals' personal experiences of bereavement over the last 5 years while the other captured responses from organisations supporting people affected by bereavement. Both surveys captured qualitative and quantitative data. A lived experience advisory forum was established to

ensure the voices of people affected by bereavement were included and considered in the both the formulation of survey questions and the identification of themes and recommendations from data collected. Qualitative data from were analysed using thematic analysis. Descriptive statistics summarised demographic characteristics of respondents, types of support received and satisfaction with support received.

Results: Challenges experienced and recommendations for future support were identified by analysing individual and organisational perspectives.

Conclusions: Understanding the experiences of bereaved people, from a range of different backgrounds and locations across the UK represents an essential first in ensuring that supports and services for those facing bereavement in the future are informed by people with direct experience of bereavement or of supporting those affected by bereavement. The Commissions plans for ensuring update of identified recommendations will also be discussed.

Abstract ID: P02:59

Abstract type: Poster

What Do Commercial Stock Images Tell Us About Palliative Care? A Multimodal Critical Discourse Analysis

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Background/aims: Media and publication companies and businesses often use commercial stock images to represent medical conditions and healthcare services, and this can have the potential to influence the public's attitudes, ideas and beliefs towards these conditions and services. Limited research has been undertaken to date to critically examine the visual discourses surrounding palliative care. The aim of this research was to analyse how commercial stock images represent palliative care.

Methods: Stock images were retrieved from Getty Images, the world's largest supplier of stock images, using search terms relevant to palliative care. The 100 'most popular' images were analysed using a multimodal critical discourse approach to study the ways in which message and meaning were conveyed.

Results: The images retrieved encompassed photographs of palliative care patients (n=55), healthcare icons and symbols (n=23), hand-holding (n=12), and other miscellaneous images (n=10). Many of the photographs of palliative care patients depicted them smiling, often seated in a wheelchair or using a walking aid. Muted colours were used for patients' clothing, with brighter colours for healthcare professionals' uniforms. Healthcare icons and symbols included healthcare professionals across a range of professions, medicines, religious and spiritual support, grief and death. Hand-holding photographs emphasised the importance of a holistic approach encompassing physical, emotional and psychosocial care. Other images depicted outlines and silhouettes, medicines, or empty rooms or wheelchairs. Although some photographs accurately depicted palliative care, many did not reflect this, but reinforced negative stereotypes and stigma.

Conclusions: Inaccurate and misleading portrayals of palliative care can enhance the stigma and stereotypes surrounding it. It is important that publishers and producers of stock images consider the negative consequences of misleading representations.

Funding: No specific grant was received to undertake this work.

Abstract ID: P02:60

Abstract type: Poster

Degree of Autonomy in Making Everyday Choices by Frail Older People With Intellectual Disabilities in a Care Home: A Descriptive Ethnographic Study

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Background/aims: Knowing how people with an intellectual disability make everyday choices may provide clues to better involve them in decision-making considering their care. We aimed to gain more insight into the degree of autonomy frail older people with intellectual disabilities have in making everyday choices in a Dutch residential care facility.

Methods: We performed a descriptive ethnographic study in a residential facility in the Netherlands. The residents were 22 persons between the ages of 54 and 89 years with mild to moderate intellectual disabilities (IQ <70) and low social-emotional development levels. In a mixed-methods design we combined participant observations and qualitative interviews. We observed the residents and their interactions, with each other, support staff and visitors.

Results: Residents indicated to be free to make daily choices, for instance concerning which clothes to wear. They stated to experience less autonomy with regard to health issues, e.g., how to deal with the corona regulations, safety, such as determining the number of dolls that can be taken outside, and guardianship, such as buying expensive items. Support staff stated that the process of determining residents' degree of autonomy begins with establishing their needs and preferences. Support staff also indicated that the degree of autonomy that is allowed depends on the characteristics of the person with an intellectual disability, the attitude of the support staff and the vision of the care institution.

Conclusions: Residents with an intellectual disability in our study had a clear view on the autonomy they experience in making everyday choices. Support staff is mindful of the importance of preserving residents' autonomy, but in practice it is limited to a few areas of life. The reasons for limiting residents' autonomy differ within the support staff.

Abstract ID: P02:61

Abstract type: Poster

Shared Decision Making for Frail People With Intellectual Disabilities in the Palliative Phase: A Process Evaluation of the Implementation of a Conversation Aid for Care Staff

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Background/aims: In palliative care for people with intellectual disabilities (ID), it is important to make decisions based on the wishes and preferences of the patients themselves. In order to better support the decision-making process for people with ID, we developed and implemented a conversation aid called In-Dialogue in four residential care facilities in the Netherlands. In this paper, we present the evaluation of the In-Dialogue training and the barriers to and facilitators for the implementation process of In-Dialogue in care.

Methods: The In-Dialogue locations were recruited based on the presence of frail residents who might be in the palliative phase. We evaluated the In-Dialogue training with a questionnaire that support staff completed immediately after they attended the In-Dialogue training. Next we invited four relatives, nine support staff members and three people with ID, who worked with In-Dialogue, to participate in semi-structured interviews. The interviews addressed the application of In-Dialogue in practice.

Results: The In-Dialogue training was rated 7.5 out of 10 by 46 participants. Practicing with In-Dialogue using self-reported cases with a training actor was felt to be valuable by most participants. Most participants stated that the In-Dialogue conversations had provided new information about, and a better understanding of, the people with ID and their families. Some participants would especially recommend In-Dialogue to support staff who find it difficult to talk about illness. A few participants found it difficult to apply In-Dialogue with people with mild ID or relatives because they were afraid that In-Dialogue could be perceived as childish.

Conclusions: This study shows that In-Dialogue can be a good tool for support staff who find it difficult to start conversations about illness/end of life, want to be sure not to forget topics in decision-making conversations, or want to build a better trusting relationship with people with ID and/or relatives.

Abstract ID: P02:62

Abstract type: Poster

Loneliness Among People Who Are Terminally Ill and Their Carers in Northern Ireland: Perspectives and Experiences of Health and Social Care Professionals

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Background/aims: Northern Ireland is currently the only region of the UK without a bespoke Loneliness Strategy. This is despite the enormous impact that loneliness may have on people with terminal illnesses and their carers, such as poor mental and physical health outcomes and lower quality of life. A Northern Ireland specific strategy is likely to be developed during the next few years but will not recognise and respond to the needs of people impacted by terminal illnesses without greater research evidence.

Aims: To explore the perceived prevalence, impact, and possible solutions to loneliness among people who are terminally ill and their carers in Northern Ireland, from the perspectives of health and social care professionals.

Methods: Explanatory sequential mixed methods comprising an online survey (n=68; response rate 30%) and three online focus groups (n=15) with Marie Curie health care professionals. Data analysis included descriptive statistics and thematic analysis. Patients and informal carers were involved in shaping the results.

Results: Data analysis is underway, and findings will be presented on the reported prevalence, impact, and possible solutions to loneliness among people who are terminally ill and their carers in Northern Ireland.

Conclusions: This study will provide an evidence base for what people with terminal illness and their carers need to help alleviate loneliness.

This evidence will inform future loneliness policy development, including a Northern Ireland Loneliness Strategy, ensuring that the experiences, voices and needs of people impacted by terminal illness are included within this strategy.

Funding: This study was funded by a Marie Curie policy-themed small research grant

Abstract ID: P02:63

Abstract type: Poster

What Factors Predict Depression Outcomes Among COPD Patients? A Cross-Sectional Survey From South Africa

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Background/aims: COPD is currently the fourth leading cause of death globally and is predicted to be the third leading cause of death by 2030. COPD patients experience psychosocial problems and concerns which may require psychosocial or spiritual support as the disease progresses. We aimed to identify the prevalence and predictors of depression among COPD patients in primary care.

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 in the last seven days) and clinical data were collected. Patients also completed the Center for Epidemiological Studies Depression Scale (CES-D), the Medical Outcomes Study (MOS), Social Support Survey, the London Chest Activity of Daily Living Scale and the COPD Assessment Test (CAT) (impairment on person's life). We analysed depression prevalence using three level cut offs: No depression (0-15), Mild depression (16-26) and Major depression (27-60). We conducted ordered logistic regression analysis to assess factors associated with burden of depression (CES-D).

Results: We recruited n=387 patients. The mean age was 59.5 years. Over half of the participants were not at risk for depression n=215 (55.5%), n=80 (20.7%) were at risk for mild depression while n=92 (23.8%) were at risk for major depression. In multivariate analysis depression was associated with a lack of social support .96 (.95 to .97); p<0.001, impairment on person's life (higher CAT scores) and inability to perform activities of daily living (higher LCADL scores) 1.07 (1.05 to 1.09); p<0.001. Depression was lower among older participants .98 (.96 to 1.01); p<0.001. Participants who missed one or more doses were 2.25 (1.25 to 4.05) times more likely to be at risk for depression.

Conclusions: The high prevalence of depression provides strong evidence of the need for integrated and holistic palliative care in primary care settings among COPD patients.

Abstract ID: P02:64

Abstract type: Poster

Early Interprofessional Collaboration Between Palliative Home Care Teams and General Practitioners for Patients With Advanced Chronic Diseases – KOPAL-Study Experiences of Palliative Home Care Teams

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Background/aims: In Germany, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF) and dementia (D) rank among the most common chronic diseases. They go along with a high rate of hospitalization and prognostic uncertainty. The study 'Strengthening interprofessional collaboration for patients with non-oncological palliative care needs – development and evaluation of a new concept: the multicenter KOPAL randomized controlled trial' facilitated an intervention for affected patients. It is composed of the KOPAL conversation guide structured Palliative Home Care (PHC) nurse home visit and a following case conference by phone for the PHC nurse, PHC physician and the general practitioner (GP). We aimed to explore PHC nurses' and PHC physicians' experiences with the KOPAL intervention.

Methods: Based on a semistructured narrative interviews experiences associated with the KOPAL intervention of 14 PHC teams (16 nurses, 10 physicians) were assessed by phone. Interviews were transcribed verbatim and analyzed using Grounded Theory Method.

Results: Participants thought that patients with COPD, CHF and D can benefit from early interprofessional cooperation of PHC teams with GPs. Early familiarization helps to strengthen a relationship of trust between patients and PHC teams for end-of-life care. In addition, PHC teams could support GPs in the informed decision making for patient specific introduction of specialized palliative care to reduce 'revolving door effects'. PHC teams often underline palliative needs of patients with advanced chronic diseases and wish more acceptance for providing PHC, especially from the organizations bearing costs in Germany.

Conclusions: KOPAL study shows experiences of PHC teams for early interprofessional cooperation with GPs for patients with COPD, CHF and D. Further research is needed to explore PHC teams' understanding about appropriate timing of (early) interprofessional cooperation.

Funding: German Innovation Fund of the Federal Joint Committee (G-BA), Funding no. 01VSF18024

Abstract ID: P02:65

Abstract type: Poster

Audit of Lung Transplant Palliative Care Clinic at the Alfred Health

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Background/aims: Lung transplant candidates experience significant symptom burden and poor quality of life, while recipients may develop graft rejection/failure complications and secondary malignancies. A specialist palliative care (PC) clinic was established at Alfred Health, Melbourne, Australia, in 2016 to improve the quality of life of lung transplant candidates, recipients, and their family caregivers. This study aims to characterise the patients seen in the lung transplant palliative care (LTx PC) clinic at Alfred Health.

Methods: Single-centre audit of hospital medical records of all patients attending the LTx PC clinic at Alfred Health between September 2016 to April 2021. The mean follow-up period was 6 months, and the average clinic attendance was 5 visits with a maximum of 13 attendances. Data were analysed using descriptive statistics on Excel, and hypothesis testing was performed using GraphPad Prism 9.

Results: 67 patients attended the LTx PC clinic during the study period. Their median age was 62 (51-67) and 49% were male. The majority (n=46, 69%) were transplant recipients. The most common primary diagnoses were chronic obstructive pulmonary disease (n=22, 67%) and chronic lung allograft dysfunction (n=19, 27.5%). Most of the patients (n=51, 76%) had

died within 12 months of their first clinic appointment. Interestingly, recipients were more likely to die during clinic follow up (P=0.033). Only 10% had an advance care directive documented (n=7). Less than half (n=30, 45%) were referred to specialist community PC services.

Conclusions: Patients seen in the LTx PC clinic at Alfred Health were mostly transplant recipients and had a poor prognosis, but only a minority had documented advance care directives or were referred to specialist community palliative care services.

Abstract ID: P02:66

Abstract type: Poster

Goals of Care Discussions with Non-English Speaking Chinese Patients in an Internal Medicine Residency Program

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Background/aims: There is limited research regarding palliative care amongst Chinese American patients. Internal Medicine (IM) residents are involved in goals of care (GOC) discussions with non-English speaking Chinese patients, but often lack training on utilization of interpreter services as well cultural beliefs of this population. To provide insight into ways to improve GOC discussions with this population and the cultural competency of IM residents, we explored resident needs and the experiences of medical interpreters at Tufts Medical Center (TMC).

Aim: 1) Investigate medical interpreters' and IM resident perceptions of barriers of effective GOC discussions with Chinese American patients 2) Create and evaluate educational intervention to address barriers

Methods: The research protocol was approved by the TMC IRB. Two focus groups were held with Chinese speaking medical interpreters. Responses were systemically collected and analyzed using open and focused coding, and thematic analysis. A needs assessment survey was electronically sent to 76 residents and they were invited to a 1-hour educational intervention discussing GOC discussions with Chinese American patients. Immediate and post-five week surveys were e-sent to residents and results were de-identified and analyzed.

Results: The interpreter focus groups revealed six themes, including concepts of palliative care and hospice are poorly understood by Chinese American patients. The resident needs assessment had a response rate of 40.8%. Experiences included a lack of shared cultural values and uncertainty of interpretation. Survey results five weeks post intervention demonstrated an increase of resident confidence, self-reported impact, skills, and knowledge.

Conclusions: Having direct input from interpreters can improve GOC conversations with non-English speaking patients. Providing education on cultural differences regarding end of life care to medicine residents is vital in having impactful discussions in patient care.

Abstract ID: P02:67

Abstract type: Poster

Integration of Palliative Care and Psychiatry: Ethico-Clinical and Organisational Challenges Based on Professionals' Views

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Background/aims: Linkages between palliative care (PC) and psychiatry are increasingly relevant, sharing common features (e.g., symptom control; quality of life; respect for patients' dignity, vulnerability, autonomy).

Aims: To understand the clinical, organisational, and ethical challenges of integrating PC for patients with severe persistent mental illness (SPMI) or severe chronic psychiatric conditions (SCPC).

Methods: Qualitative study with in-depth interviews.

Participants: Professionals working in acute and long-term psychiatric services/institutions in Portugal.

Sampling procedure: Purposive and snowball until theoretical saturation.

Data collection: Ongoing; up-to-date 11 professionals interviewed.

Analysis: Data is being analysed using inductive thematic analysis.

Results: Four main themes with sub-themes emerged: (i) Integration through liaison of psychiatry and PC (patients in PC are referred to psychiatrists to assess and manage acute psychiatric disorders or wishes to hasten death); (ii) Inequities in access of patients with SCPC to specialist PC (patients with SCPC are often neglected in their clinical complaints; even when these patients have a physical life-threatening disease and PC needs requiring specialist PC, they often do not have access to this type of service especially when compared to other patients; as patients with SPMI do not have access to specialist PC, integration could be fostered through training about PC); (iii) Palliative psychiatric care (application of the core components and principles of PC to the care of patients with SPMI, particularly those who are at risk of therapeutic neglect and/or overly aggressive care; awareness of limited functional prognosis and lifespan of patients with SPMI; care focused on quality of life); and (iv) Impracticability of integration (psychiatrists do not consider PC or end-of-life care within the scope of their practice).

Conclusions: The integration of PC for patients with SPMI can be an effective response for these patients and their families.

Abstract ID: P02:68

Abstract type: Poster

“No One Can Tell Me How Parkinson’s Disease Will Unfold”: A Mixed Methods Case Study on Palliative Care For People With Parkinson’s Disease and Their Family Caregivers

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Background/aims: Palliative care for persons with Parkinson’s disease (PD) is developing. However, little is known about the experiences of patients with PD in the palliative phase and of their family caregivers. The aim of this study is to explore needs of patients with PD in the palliative phase and of their family caregivers

Methods: A mixed methods case study design. Health care professionals included patients for whom the answer on the question “Would you be surprised if this patient died in the next 12 months?” was negative. At baseline, and after six and twelve months, we conducted semi-structured interviews with patients and caregivers. Participants completed questionnaires on quality of life, disease burden, caregiver burden, grief and positive aspects of caregiving.

Results: Ten patients and eight family caregivers participated, of whom five patients died during the study period. While the quantitative data reflected a moderate disease burden, the qualitative findings indicated a higher disease burden. Longitudinal results showed small differences and changes in time. Patients reported a diverse range of symptoms which had a tremendous impact on their lives. Nevertheless, they rated their overall quality of life as moderate to positive. Family caregivers gradually learned to cope with difficult situations such delirium, fluctuations in functioning and hallucinations. Patients sensed a lack of time to discuss their complex needs with clinicians. Furthermore, palliative care was rarely discussed, and none of these patients had been referred to specialist palliative care services.

Conclusions: Patients with PD experienced many difficulties in daily living. Patients seem to adapt to living with PD as they rated their quality

of life as moderate to positive. Family caregivers became experts in the care for their loved one, but often learned on their own. An early implementation of the palliative care approach can be beneficial in addressing the needs of patients with PD and their family caregivers.

Clinical Condition and Care Process

Abstract ID: P03:01

Abstract type: Poster

Efficacy of Different Opioids in Cancer Related Pain: Building a Prediction Model Based on Aggregated Data of Five RCT’s

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Background/aims: Opioids are often necessary in the treatment of cancer related pain. However, it is hard to predict the effectiveness in the individual. Therefore, we aim to assess the association between patient/pain characteristics and opioid treatment response in cancer patients, and to develop a model to predict response of five strong opioids.

Methods: Via PubMed we selected RCT’s on the effectivity of strong opioids in cancer pain between 1994 and 2020. Authors were approached to share their raw data. Raw study-level data were aggregated and missing data were imputed using multiple imputation. The primary outcome is $\geq 50\%$ reduction in pain at one week after opioid treatment initiation. Secondary outcomes are $\geq 30\%$ reduction in pain at the short-term (one week) and long-term (four/five weeks) and opioid-increase ratio. We will use a logistic regression model (LRM) to compute the unadjusted associations between determinants and actual treatment success. Subsequently, the determinants will be adjusted in a multivariable LRM. To develop the final prediction model, we will enter all determinants in a LRM using backward stepwise elimination. Variables that will be selected in over half of the imputed datasets will be selected for the prediction model. The performance of the prediction model will be quantified by measures of discriminative ability (area under the receiver-operating characteristic curve (AUC)) and calibration.

Results: The Pubmed search revealed 29 RCT’s. Of the approached authors seven had no longer access to the data and 17 did not react. Data of 5 studies will be used in the analyses: Corli et al. 2016 (n = 498), Haumann et al. 2019 (n=134), Nosek et al. 2017 and Leppert & Nosek 2019 (n=62) and Zecca et al. 2016 (n=187). In total 881 patients. First results indicate morphine as superior over the other opioids on the primary outcome.

Conclusions: With the prediction model we hope to create a tool assisting the choice of the right opioid for the individual patient with cancer related pain.

Abstract ID: P03:02

Abstract type: Poster

Physicians’ and Nurses’ Experience of Using the Abbey Pain Scale (APS) in People with Advanced Cancer: A Qualitative Content Analysis

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Background/aims: The Abbey Pain Scale (APS) is an observational scale for assessing pain in people with end-stage dementia, but it is also used in Sweden to assess pain in patients with advanced cancer. It is unclear whether using the APS is appropriate in this context.

The aim of this study is to explore physicians' and nurses' experience of using a Swedish translation of the APS (the APS-SE) in people with advanced cancer.

Methods: Qualitative content analysis was used to analyse interviews with physicians and nurses working in oncology and specialised palliative care about their experiences of using the APS-SE.

Results: The interviewees concluded that the APS-SE provides them support in a difficult situation; however, it sometimes misses the mark. It does not distinguish well between pain and other types of suffering, and staffs' intuitive perceptions of patients' suffering tend not to match the APS-SE pain score. The APS-SE is not seen as ideal in this clinical context since some parts are not considered useful and others are perceived as unethical.

Conclusions: There is a great need for a pain assessment tool for people with advanced cancer. The APS-SE is helpful but is not perceived as ideal in this context. Its problems are inherent in the original APS and not considered to be related to its translation from English to Swedish. Further research is needed to provide a more suitable pain assessment tool for patients with advanced cancer.

Abstract ID: P03:03

Abstract type: Poster

Non-steroidal Anti-inflammatory Drugs (NSAIDs) in Cancer Pain: Testing Patient Eligibility for Recruitment to a Clinical Trial

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Background/aims: Insufficient quality evidence exists to support or refute the use of non-steroidal anti-inflammatory drugs (NSAIDs) in the management of cancer pain. Palliative physicians support a placebo-controlled trial of NSAIDs as strong opioid adjuncts for cancer-induced bone pain (CIBP) as the most pragmatic design to benefit clinical practice. We aimed to determine the number, demographics and co-morbidities of palliative patients receiving radiotherapy for CIBP, guiding the feasibility of a future trial.

Methods: Five years of retrospective radiotherapy data from the regional Leeds Cancer Centre were filtered (94% sensitive, 90% specific) to achieve a palliative cohort with CIBP. Demographics and survival were linked to available serology and co-morbidity data. Linear regression and descriptive statistics were used.

Results: Over five years, 2411 patients received palliative radiotherapy for CIBP in Leeds (mean 478 patients/ year). Median age (IQR) was 70 (62-77); negatively skewed (-0.69). More were male (58%). 61.8% died within 1 year of radiotherapy; 46.6% within 6 months. Age did not correlate with survival duration, $r(1878) 0.015$, $p=0.51$. A minority (30.1%) underwent further radiotherapy on subsequent dates. During the 6 months prior to radiotherapy, blood results from 1063 (44.2%) patients were available; eGFR was $\geq 90\text{mL/min/1.73m}^2$ in 47.0% and $\geq 60\text{mL/min/1.73m}^2$ in 83.0%. Similarly, a minority had markers of impaired synthetic liver function (platelets $< 150 \times 10^9/\text{L}$ in 7.9%; bilirubin ≥ 21 in 3.4%; INR ≥ 1.2 in 20.5%), excluding hypoalbuminaemia (54.1%). From available data (51.6% of sample), 20.2% had a coded co-morbidity contra-indicating NSAID prescription. Combining serological (eGFR $> 60\text{mL/min/1.73m}^2$) and contra-indicated co-morbidity data, 47.6% of this population could be considered for NSAID prescription.

Conclusions: Patient numbers at a single regional radiotherapy centre support the feasibility of trial recruitment. Available serology and

co-morbidity data suggest half may be suitable for NSAID prescription. This may be an underestimate, considering data limitations. Concerning survival post radiotherapy, NSAIDs could provide sustained benefit for this population if proven efficacious.

Abstract ID: P03:04

Abstract type: Poster

Effectiveness in Radium-223 Treatment for Pain Bone Metastasis in Castration-Resistant Prostate Cancer

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Background/aims: Radium-223 (Ra-223) is an α -particle emitting radiopharmaceutical that in symptomatic bone metastases castration-resistant prostate cancer exerts a direct cytotoxic effect.

It improves the quality of life in these patients, mainly on cancer pain, increasing the time to analgesic radiotherapy and reducing the risk of pathological fracture. It also reduces the appearance of new bone events and spinal cord compression and increases survival, with good tolerance and profile of adverse effects.

Methods: 79-year-old patient with no relevant history who was diagnosed in 2014 with adenocarcinoma of prostate treated with androgen blockade and radiotherapy. At 6 months, he was diagnosed with C3-C4 spinal cord compression receiving palliative radiotherapy, with pain relief. Since then he received various therapeutic lines with remote disease control until 2016, which coinciding with an elevated PSA, the patient reported disabling pain at the lumbar level, which did not subside with pharmacological treatment. Bone gammagraphy showed progression in the thoracolumbar spine and pelvis. Given the symptoms of pain and poor evolution of the disease treatment with Ra-223 was started.

Results: The patient presented significant clinical improvement, with pain control from the first dose and controlled disease for almost a year. In a posterior control bone gammagraphy progression was evidenced, stopping treatment and starting a new line of hormonal treatment.

Conclusions: Ra-223 administration was associated with a meaningful pain response in this patient. Therefore, Radium-223 should be considered as a therapeutic option in this patient profile.

Abstract ID: P03:05

Abstract type: Poster

Radiotherapy and Gynecological Cancer Pain: A Case Report

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Background/aims: Radiation therapy is an effective treatment for cancer pain. In bleeding gynecological tumors it also has an important role as a hemostatic agent. The control of pain is fundamental in the quality of life of the terminal patient. The multimodal treatment is the best strategy in pain control. In this report we show the results of a patient with a vaginal carcinoma who has required multidisciplinary management to control pain.

Methods: 71-year-old patient with vulvar lichen who consulted about 4 months of vaginal pain and foul-smelling leukorea. Gynecological examination reveals a bloody lesion close to the introitus causing stenosis of the vagina. The vaginal tumor was excised, with the pathological result of infiltrating squamous-cell-carcinoma with poorly differentiated areas. 1 month later, a control MRI revealed a voluminous 12cm vaginal tumor, infiltrating rectal mucosa. The CT scan shows the presence of pulmonary

metastases (Stage IVb). In colonoscopy, a rectal biopsy was performed, resulting in infiltration by poorly differentiated squamous-cell carcinoma, with areas of sarcomatoid transformation. The patient reported a baseline Visual Analog Scale (EVA) 8 pain, EVA 10 after the deposition, which did not subside with regular analgesia.

Treatment with transdermal Fentanyl was prescribed, reaching doses of 100mcg/72h and rescues with sublingual Fentanyl of 100mcg, and palliative external radiotherapy was administered on the vaginal lesion, 30 Gy with a fractionation of 3 Gy/day, 10 treatment fractions.

Results: Treatment with radiotherapy showed a significant response on tumor volume and bleeding. Pain was controlled with the multidisciplinary management.

Conclusions: Radiation therapy is an effective treatment in the control of pain in cancer patients, being able to achieve pain control as an exclusive treatment or in combination with other treatments. The case presented is an example of the good response to multidisciplinary treatment in a patient with severe cancer pain.

Abstract ID: P03:06

Abstract type: Poster

Audit: To Assess if Breakthrough Opiate Analgesic Dose Is Appropriately Calculated for Palliative Care Patients in an Acute Hospital

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Background/aims: Breakthrough pain relates to a transient exacerbation of pain. Breakthrough pain is common amongst palliative care patients and has a deleterious effect on quality of life. The breakthrough dose of immediate release opiate analgesic is usually calculated as 1/6 of the total 24 hour background opiate dose and administered via a variety of routes. The aim is to assess if the dose of breakthrough oral and subcutaneous immediate release analgesic is calculated as 1/6 of the total 24 hour background dose.

Standard: Calculation of breakthrough dose as recommended by National Clinical Effectiveness Committee Ireland: Pharmacological management of cancer pain in adults, national clinical guideline no. 9 (2015).

Methodology: Patients referred to palliative medicine over a 2 week period in April 2021 were reviewed for suitability. Those who were on a background opiate were selected for inclusion. Their medical notes and prescription charts were reviewed and it was recorded if their breakthrough dose of immediate release oral morphine was calculated as 1/6 of their 24 hour background opiate dose or not. Medical notes were reviewed to investigate if there was a reason for alternative calculation of breakthrough analgesic dose.

Results: 1st cycle of audit: 20 patients met the inclusions criteria (17) 85% had their breakthrough dose calculated appropriately.

Intervention: At a palliative medicine department meeting the audit findings and an educational session on the above guideline were presented.

Re-Audit: Three weeks after the intervention, over a 2 week period in June 2021, 22 patients met the inclusion criteria for the re-audit, which revealed 100% compliance with the guideline.

Conclusions: An education session on the national clinical guideline optimised adherence with the guideline regarding calculation of breakthrough dose. Recommendation from this audit is an education session on this guideline for palliative medicine doctors at the start of their hospital rotation.

Abstract ID: P03:07

Abstract type: Poster

Systematic Review of Safety in Re-Irradiation of the Spine as Treatment in Cancer Pain

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Background/aims: The objective in this review is to analyze the risk of post-radiotherapy myelitis in patients with spine reirradiation treatment due to cancer pain.

Methods: A series of articles related to the risk of myelitis due to spinal reirradiation in patients with painful bone metastases was reviewed in available literature. Keywords as "reirradiation", "spinal cord" and "myelopathy" have been used in the search, obtaining a total of 75 articles. It has been made a selection of English language written articles published in the last fifteen years. It has been studied a total of 259 patients with good analgesic response in a first irradiation session who have been irradiated again later. The received dose in each irradiation, the cumulative biological equivalent dose (BED), the response to pain and the associated neurological toxicity have been analyzed.

Results: Of all patients, pain response was good in more than 90%, without myelitis in any case. The maximum cumulative BED was 120 Gy. The average interval was 14 months.

Conclusions: Radiation therapy is a highly relevant analgesic treatment in painful bone metastases, obtaining a rapid, effective and sustained response in most patients. Reirradiation is effective and safe as long as it is carried out with caution evaluating the dose received in each treatment, the cumulative BED and the time interval between each irradiation. The authors consider a low risk of myelopathy if it is administered more than 6 months apart, with a total dose of less than 98 Gy and a cumulative BED of less than 120 Gy.

Abstract ID: P03:08

Abstract type: Poster

Identification and Susceptibility Testing of Oral Candidiasis in Advanced Cancer Patients – An Important Diagnostic Tool

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Background/aims: *Candida albicans* is the most common fungal species detected in the oral cavity. Studies of oral fungal samples have shown an increased prevalence of non-*C. albicans* species in mixed infection with *C. albicans*. Non-*C. albicans* and *C. albicans* are associated with varying degrees of resistance to azole. This may have implications for treatment, due to acquired antifungal drug resistance.

The aim of this study was to assess the diversity and susceptibility of detected *Candida* species in the oral cavity in patients with advanced cancer.

Methods: Clinical fungal isolates sampled in 2014–2016 from 45 patients in a hospice unit were analyzed. A total of 52 isolates were grown on chromID Candida plates. After phenotypic identification by colour of the colonies, one single colony of each species was re-cultivated and prepared for identification on a VITEK2[®] system. Susceptibility testing with E-test was performed on RPMI agar, and the antifungal agents fluconazole, amphotericin B, anidulafungin and nystatin were tested.

Results: A total of 56 isolates were identified. The diversity of *Candida* species was dominated by *C. albicans* at 89%, followed by *C. glabrata* 11%, *C. parapsilosis* 7%, *C. tropicalis* 4%, *C. krusei* 2%, *C. guilliermondii* 2% and *C. dubliniensis* 2%. Thirty-six patients had monoculture, and nine patients had 2-3 different species detected. Almost all *C. albicans* strains (97.5%) were

susceptible to fluconazole. One *C. parapsilosis* and one *C. tropicalis* strain were resistant to anidulafungin. One *C. glabrata* was resistant to fluconazole and another was just below the threshold for resistance.

Conclusions: *C. albicans* was the most prevalent *Candida* species in our sample. Variation in susceptibility was observed in patients with both *C. albicans* and *C. glabrata*. Combinations of *Candida* species and the lack of identification and susceptibility testing may lead to inadequate treatment and accelerate the development of resistance.

Abstract ID: P03:09

Abstract type: Poster

Experiencing Panic In Breathlessness Episodes is Influenced by Breathlessness-related Catastrophizing Thoughts

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Background/aims: Episodic breathlessness is characterized by increased symptom intensity, often accompanied by panic. A vicious cycle of breathlessness-panic-breathlessness leads to emergencies that can rarely be alleviated by drugs. However, the interaction between episodic breathlessness and panic is not well understood.

How does panic interact with episodic breathlessness and what leads to panic in episodic breathlessness?

Methods: Between 02/19 and 02/20 patients with life-limiting diseases, suffering from episodic breathlessness, answered questions on characteristics of episodic breathlessness and panic-spectrum psychopathology including its underlying mechanisms. They were screened for panic using the Patient Health Questionnaire (PHQ).

Results: 46 patients (52% women, with a mean age of 66; $SD = 7.3$) provided information: 60 % suffered from panic during the entire breathlessness episode, 38 % experienced panic in every episode, 25 % were screened positively for panic (PHQ). Those patients with high scores in breathlessness catastrophizing thoughts experienced more panic in a breathlessness episode ($z = -3.49$; $p < .001$; $r = -.56$) and considered themselves more panicky than those with low scores ($z = -2.25$; $p = .024$; $r = -.35$). There was a significant indirect effect of episodic breathlessness' intensity on experienced panic in an episode through catastrophizing thoughts regarding breathlessness ($b = .164$; 95% CI [.105, .222]).

Conclusions: Given the psychological factors that contribute to patients' experiences with episodic breathlessness, psychotherapeutic treatment is promising in supporting patients to manage panic in episodic breathlessness. They should not focus only on panic in breathlessness episodes but also on underlying mechanisms as catastrophizing thoughts as they may maintain or aggravate the panic.

Abstract ID: P03:10

Abstract type: Poster

Effectiveness of an Algorithmic Approach to Ventilator Withdrawal at the End of Life

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Background/aims: The transition to spontaneous breathing puts patients that are undergoing ventilator withdrawal at highest risk for respiratory distress. The approach to this care process is often reliant on local unit custom. A patient-centered algorithmic approach is needed.

Aims:

- 1) Demonstrate that the algorithmic approach is effective to ensure greater patient respiratory comfort compared to usual care;
- 2) Determine whether algorithm-guided withdrawal will be associated with differences in opioid or benzodiazepine use compared to usual care.

Methods: Patients are randomized into algorithm and usual care groups using a stepped-wedge cluster randomized clinical trial design. Sites crossed over to the algorithm in random order after usual care data were obtained. Patient comfort was measured with the Respiratory Distress Observation Scale (RDOS) at baseline, at ventilator off, and every 15-minutes for an hour. Parenteral morphine and lorazepam equivalents from the onset of the process until patient death were used. The algorithm prescribes either ventilator weaning, or one-step cessation based on patients' distress and baseline consciousness; medication use is guided by RDOS scores.

Results: Presently, usual care data $n=120$, algorithm data $n=48$. Gender and race (white or black) were evenly distributed. All patients in the usual care arm underwent a one-step ventilator cessation; 58% of patients in the algorithm arm were weaned over an average of 18 ± 27 minutes. Patients had lower RDOS scores in the algorithm arm at the time the ventilator was turned off ($t=-2.8$, $p=.006$), at 15-minutes ($t=-2.34$, $p=.021$), and at 30 minutes ($t=-1.92$, $p=.057$). More opioids ($t=-2.30$, $p=.023$) and benzodiazepines ($t=-2.08$, $p=.040$) were given in the control arm.

Conclusions: The algorithm is effective in ensuring patient respiratory comfort. Of surprise more medication was given in the usual care arm, however, less may be needed when distress is objectively measured (RDOS) as in the algorithm.

Abstract ID: P03:11

Abstract type: Poster

Development of Treatment Recommendations for Dealing With Off-Label Drug Use in Palliative Care

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Background/aims: The key element of palliative care treatment is the control of distressing symptoms. In pharmacological treatment approaches, up to 50% of drugs are used off-label (OLU), e.g., in a different indication, route of administration, or dosage. In OLU the potential risks to patients from a drug that has not been adequately tested must particularly be taken into account. In everyday clinical practice, though, there is often a lack of time and resources to carry out a patient-specific risk-benefit assessment on the basis of the current literature and available alternatives. So far, specific consensus- and evidence-based therapy recommendations are only available to a very limited extent.

The aim of this project is to develop therapy recommendations for the OLU of drugs relevant in palliative care.

Methods: After identifying relevant drugs and indications for palliative care, a systematic literature search is conducted for each drug and its use in the

Cochrane, Medline, and Embase databases to identify relevant publications. The evidence is then extracted and evaluated according to the SIGN grading system. Based on this data, explicit off-label treatment recommendations will be drafted and consented via an internet-based Delphi process with palliative care experts from medicine, pharmacy, and nursing in Germany.

Results: The first Delphi process will be conducted in early 2022. The results will be made available in the form of monographs on a freely accessible website for professionals. Healthcare professionals will receive a comprehensive, evidence- and consensus-based source of information to support OLU in clinical practice. The recommendations will also include information on approved or better-documented alternatives, non-drug measures, and parameters for treatment monitoring.

Conclusions: This project aims to close an information gap and provide low-threshold access to recommendations in order to make an important contribution to drug therapy safety. Funding: German Cancer Aid.

Abstract ID: P03:12

Abstract type: Poster

Understanding the Levers and Barriers to using Cannabinoid-Based Medicines in Palliative Care: According to the Representations and Experiences of Patients

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Background/aims: Cannabinoids-based medicines (CBM) are currently very little used in palliative care

The aim was to identify patients representations and experiences of the use of CBM and to analyse the associated levers and barriers to their prescription

Methods: A qualitative study involving semi structured in-depth interviews with 10 patients hospitalized in a palliative care unit. The data were analyzed using the Interpretative Phenomenological Analysis method.

Results: A majority of patients were in favor of the use of CBM in palliative care. They made clearly the distinction from recreational use, however they report a lack of medical information on these products, whether theoretical or clinical. They wonder about the monitoring and the routes of administration of treatments.

In the context of their current situation they do not see the need to use it, either because their treatments are effective, or because they fear significant financial costs compared to the potential effects, especially on pain.

Conclusions: Informative documentation should be developed for patients to reduce the negative view of cannabis by some and to promote its beneficial effects.

Abstract ID: P03:13

Abstract type: Poster

Psychoeducational and Rehabilitative Intervention to Manage Cancer Cachexia for Patients and Their Caregivers: Single-Arm Feasibility Trial

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Background/aims: Half of all patients with cancer experience cachexia, with the prevalence rising above 80% in the last weeks of life. Cancer cachexia (CC) is a complex relational experience that involves the

patient-family dyad. There are no studies on the association between the psycho-educational component and the rehabilitative component of dyads for supporting in the management of CC.

Aims: 1) To evaluate the feasibility of a psycho-educational intervention combined with a rehabilitative intervention on dyads; 2) To evaluate the quality of life and acceptability of the intervention.

Methods: Non-pharmacological interventional perspective, mixed-method study, addressed to 30 cancer patients with cachexia and refractory cachexia and their caregivers assisted by Hospital Palliative Care Unit. The intervention includes: 1) psycho-educational session: 3 weekly consultations with nurses, helping to cope with CC strengthening dyadic coping resources; 2) Rehabilitation program: 3 sessions with physiotherapists including educational component for self-management on physical activity, personalized program of stretching and relaxation + 3 home sessions per week, self-managed by dyads. Quantitative and qualitative evaluations were performed.

Results: We enrolled 24 dyads, 12 of them completed the intervention for both components (6 meetings); 5 dyads completed $\geq 50\%$ for both components (4 meetings). Most of drop-out was related to worsening conditions. The median age of the all patients was 66; most patients were male (58%), with KPS >70 , reversible cachexia (83%), pancreatic (25%) and lung cancer (21%). The most of caregivers were spouses (87.5%).

Conclusions: The dyads appreciated to participate in a non-pharmacological cachexia study with their caregiver, with positive impact on their relationship. Due to the possible worsening of clinical conditions, shortening the duration of the intervention could be a strategy to improve adherence for frail patients.

Abstract ID: P03:14

Abstract type: Poster

Do Subjective and Objective Cognitive Performances Coincide in Advanced Cancer?

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Background/aims: Cognitive dysfunction may influence decision making, self-perception, and existential well-being in patients with advanced cancer causing more suffering. This study analyzed associations between objective neuropsychological measures and patients' self-report of cognitive dysfunction interfering with everyday life, general well-being, and sense of existential value.

Methods: Mixed method study with 13 adult patients with advanced cancer assessed by validated neuropsychological tests (objective assessment). Semi-structured interviews focusing on subjective experiences of cognitive dysfunction were also applied (subjective assessment). Agreement between subjective and objective measures was analyzed by Cohen's Kappa (k). Thematic analysis was performed.

Results: Twelve patients had complaints of cognitive dysfunction and also possible deficits in the objective cognitive performance. However, the agreement between the two assessments was weak ($k \leq 0.264$). Cognitive dysfunction challenged the patients with regard to practicing everyday life including their existential values related to the meaning of

life and well-being. Adjustment of the sense of living according to one's existential values and changes of self-perception were related positively and negatively to existential well-being.

Conclusions: Objective and subjective measures of cognitive function may not coincide but complement each other and add value to understand patients' experiences of cognitive dysfunction and the impact on their daily life and existential well-being.

Funding: This study was supported by The Research Fund of The University of Southern Denmark and The Danish Cancer Society (R62-A4017-12-S3).

Abstract ID: P03:15

Abstract type: Poster

Multidisciplinary Quality Improvement (QI) Project: Improved Management of Diabetes in the Last Days of Life

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Background: Approximately 463 million adults worldwide have diabetes, which is expected to rise to 700 million by 2045. The rise in incidence of diabetes will be paralleled by a rise in the proportion of people who die with or as a consequence of diabetes. The goal of diabetes care at end of life (EOL) is to reduce unnecessary interventions whilst minimising symptoms of hyperglycaemia and hypoglycaemia and prevent diabetes related emergencies such as diabetic ketoacidosis (DKA) and hyperosmolar hyperglycaemic state. In an acute hospital setting diabetes is frequently sub optimally managed at time of referral to palliative medicine for EOL care, which may lead to unnecessary suffering.

Aim and Objectives: The goal of this quality improvement initiative was development of a local guideline that outlines appropriate management of diabetes during the last days of life in an acute hospital setting.

Methods: Recommendations regarding appropriate management of diabetes at end of life developed by Diabetes UK, Joint British Diabetes Societies for Inpatient Care and American Diabetes Association were consulted. The palliative team discussed the management of diabetes during last days of life with different stakeholders including diabetes, care of elderly and hospice specialists. A number of QI methods were employed; such as stakeholder map, root cause analysis and plan-do-study-act cycles.

Results: Inappropriate management of diabetes at EOL was due to a lack of understanding of the need to tailor diabetes management to ensure maximal comfort. This lack of knowledge results in unnecessary burdensome interventions, osmotic symptoms and also risk of metabolic complications. To address this knowledge gap a local guideline was developed to guide management of diabetes at EOL.

Conclusions: Individuals with diabetes have a unique set of care needs at EOL. This project employed a multi-speciality QI approach to improve management of diabetes during the last days of life.

Abstract ID: P03:16

Abstract type: Poster

Experiences of Primary Healthcare Professionals With Psychosocial Support for Reduced Ability to Eat in Patients With Advanced Cancer: A Qualitative Interview Study

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Background/aims: Primary healthcare professionals (PHCPs) are increasingly involved in the care for patients with advanced cancer who often suffer from nutritional problems. However, patients and informal caregivers indicate that nutritional care is often focused on nutritional intake and that they miss attention for the psychosocial consequences of problems with eating. The aim of this study was to gain insights into PHCPs' experiences with providing psychosocial support to patients with advanced cancer having problems with eating and their informal caregivers.

Methods: A qualitative interview study with 40 primary healthcare professionals involved in care for patients with advanced cancer was conducted. All interviews were recorded, transcribed verbatim and thematically analysed using ATLAS.ti 9.0.22.0

Results: Primary healthcare professionals and not patients or informal caregivers mostly initiated the conversation about reduced ability to eat and its psychosocial impact. However, not all PHCPs were aware of this psychosocial impact. When patients or informal caregivers initiated the conversation, they mostly mentioned it implicitly. The psychosocial support for reduced ability to eat provided by PHCPs entailed listening, normalising emotions, giving practical advice, explaining nutritional complaints and involving informal caregivers in care. Facilitators for this support were home visits and multidisciplinary collaboration. Barriers mentioned were lack of knowledge regarding reduced ability to eat, lack of exchange of professional expertise, lack of access to other PHCPs, and lack of continuity of care.

Conclusions: Primary healthcare professionals have an important role in addressing the psychosocial impact of problems with eating in patients with advanced cancer and their informal caregivers. However, awareness and knowledge about this psychosocial impact need to be improved potentially by multidisciplinary collaboration and more exchange of expertise between primary healthcare professionals

Abstract ID: P03:17

Abstract type: Poster

Phase I/II Dose Ranging Study of the Pharmacokinetics, Dose-Response Parameters and Feasibility of Vaporised Botanical Cannabis Flower Bud in Advanced Cancer

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Background/aims: Cannabinoids can increase appetite in people with non-malignant conditions. Despite promise in phase II clinical trials, the role of cannabinoids in improving appetite in cancer, and the optimal dose and delivery, remains inconclusive. This study aimed to determine the pharmacokinetics of standardised vaporised cannabis flower bud (Bedrobinol® Flos) and to obtain preliminary data on appetite and quality of life.

Methods: Single arm, single blind, multiple ascending dose study of vaporised delta-9-tetrahydrocannabinol (THC) in cannabis flower bud three times a day (escalating from 0 to 48mg Bedrobinol (0-6.48mg THC content per dose)) one hour before meals over seven days. Participants were adults with advanced cancer and had anorexia for at least two weeks unresponsive to the optimisation of causative medical conditions. Blood samples at each new dose level were collected at 1, 5, 20, 40, and 60 mins, and 4 hours post dose. Patient-reported measures assessed

appetite, side effects/toxicity and quality of life. PK parameters were calculated from plasma THC concentration-time data. Non compartment analysis (NCA) was used to calculate the AUC, C_{max} and investigate the THC dose proportionality.

Results: The study recruited 13 participants (female n=7) (n=1 withdrew on day 1) with mean age of 66.6 years (range 51-82). The dose-concentration relationship of THC via a vapouriser displayed standard pharmacokinetic assumptions with exponential increase between 16 and 32 mg, consistent with standard first order pharmacokinetics, and displays linear kinetics on elimination. Dose proportionality may hold at doses of 8mg, 16mg and 32mg. Appetite numerical rating scores improved from baseline to day 8, and which was sustained at day 14. FAACT anorexia cachexia subscale increased by day 8 and remained higher than baseline at day 14. No serious adverse events were reported.

Conclusions: Vaporised cannabis merits further evaluation and these findings provide robust pharmacokinetic parameters to guide future research.

Abstract ID: P03:18

Abstract type: Poster

Prophylactic Antibiotic Therapy of Urinary Tract Infections in Palliative Care

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Background/aims: The urinary tract infections (UTI) are one of the most frequent infections in palliative care, with a prevalence ranging between 2.6 and 66%. In the general population, antibiotic prophylaxis has specific indications, especially in recurrent UTI and in some urological procedures. Considering the recommendation of early referral for Palliative Care which results on a longer follow-up of these patients, it is becoming necessary to resume the evidence of prophylactic antibiotic therapy of Urinary Tract Infection in Palliative Care, which is the main goal of this study.

Methods: An evidence-based review was performed with the following inclusion criteria: studies with patients receiving palliative treatment with a prophylactic antibiotic therapy for the development of UTI; incidence or prevalence of UTI as an outcome of the study.

A research was conducted using MeSH and non-MeSH terms "urinary tract infections" and "palliative care" in some databases - National Institute for Health and Care Excellence, Canadian Medical Association Practice Guidelines InfoBase, Cochrane Library, DARE, Web of Science, Scopus, TRIP Database and PubMed Clinical Queries. Author selected clinical guidelines, systematic reviews, meta-analyses and clinical trials in progress or published until 13th november 2020, written in English.

Results: A total of 1007 articles fulfilled inclusion criteria. There were no studies that answered directly to the raised question. Two of the articles presented the impact of UTI preventive measures in palliative care patients, although they do not specifically refer to antibiotic prophylaxis.

Conclusions: The lack of studies reflects an increasing concern with the proper use of antibiotic therapy rather than with the prophylaxis of UTI in palliative care.

More than a direct answer to the initial question, this work raises the necessity to investigate the effectiveness of antibiotic prophylaxis in this population, in specific clinical situations such as recurrent UTIs.

Abstract ID: P03:19

Abstract type: Poster

Psychological Distress during Hospitalisation in People with Advanced Chronic Obstructive Pulmonary Disease: A Qualitative, Phenomenological Study

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Background/aims: Psychological distress often occurs in people living with advanced chronic obstructive pulmonary disease (COPD). People who are hospitalised experience a higher psychological distress than at other times. Unaddressed psychological distress during hospitalisation leads to reduced quality of life, depression and risk of readmissions. Therefore, it is important to understand psychological distress and the coping strategies utilised during hospitalisation.

Methods: A qualitative, phenomenological study design was employed. Adult participants with advanced COPD who were currently hospitalised were recruited from a tertiary care hospital. Face-to-face, unstructured interviews were conducted while being hospitalised. Interviews were audio-recorded and transcribed. Data analysis followed Giorgi's descriptive phenomenological method, focused on identifying themes related to psychological distress during hospitalisation.

Results: Fifteen participants were included. Three overarching themes were identified:

- 1) Perception of incurability: Deteriorating health condition with fatigue causing dependency, and futility of treatment indicated incurability. Dependency and feelings of helplessness contributed to psychological distress.
- 2) Anxiety: People continued to experience anxiety and panic attacks despite repeated hospitalisations, which impacted their quality of life.
- 3) Finding meaning: Finding meaning through religious beliefs and continuing to trust God helped participants cope with psychological distress during hospitalisation.

Conclusions: Psychological distress remains largely unidentified in hospitalised people with advanced COPD, as indicated by recurring psychological problems. Self-coping strategies centred on religious beliefs seemed to be a helpful coping mechanism in these participants. Identification of distress, referral to appropriate psychological support and involving palliative care at the earliest, in order to provide a holistic care, are suggested ways to minimise psychological distress.

Abstract ID: P03:20

Abstract type: Poster

Gratitude Letters From Patients in Palliative Care and Their Caregivers: A Qualitative Analysis

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Background/aims: We deployed a gratitude intervention (writing and sharing a gratitude letter) for palliative patients and their relatives. Adopting a constructivist framework, we investigate what participants wrote about and beyond gratitude – understood as reflecting broader socio-cultural relations and representations about what is important to tell close ones at the end of life.

Methods: 22 patients and 12 caregivers gave us their letters. Using an inductive qualitative method, two researchers independently coded 6 randomly selected letters. As their level of agreement was over 90%, one researcher continued coding and developed themes. The other did a final crosscheck.

Results: Focusing on direct expressions of gratitude, people were thankful for the other's love and presence, writing thank you "for loving me", "for having been in my life", for being who they are, their "kindness" and

“generosity”. Participants wrote about their relatives’ support, evoking how the other is “entirely present” or does “everything” throughout the illness.

Beyond expressing gratitude, people wrote about the life they shared with the other, filled with love, “vivid joy” and “happiness of having you”. Many evoked living with the illness in terms of suffering or as a brave fight, with the other “always by my side”. A few people wrote about the end of life, as something “difficult” which they “can’t imagine”, or as a departure “towards the stars”. Several participants noted that writing helped them express their feelings.

Conclusions: In their letters, palliative patients and their relatives expressed gratitude for the other’s presence, love, support and kindness, which are largely intangible objects of gratitude. This contrasts sharply with materialistic pursuits associated with our consumer societies and suggests that at the end of life, what people recall most vividly and choose to express are narratives of shared emotions and experiences.

Abstract ID: P03:21

Abstract type: Poster

Understanding Caregivers’ Knowledge, Representations and Fears Regarding the Introduction of Psychedelic-Assisted Psychotherapy to Terminally Ill Patients With Existential Distress

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Background/aims: Current management of existential distress, commonly found in palliative care, suffers from limited effectiveness. Psychedelic-assisted psychotherapy (PAP) offers an innovative and effective approach to addressing this distress.

The aim of this study was to understand the knowledge, representations and possible apprehensions regarding the introduction of the PAP of health professionals working in a palliative care division and to identify whether they differentiate between recreational and therapeutic use of psychedelics.

Methods: We conducted semi-structured interviews with 13 caregivers of our palliative care division. The data were processed by thematic analysis, in order to highlight trends in the participants’ discourses and experience.

Results: One third of the health professionals tolerate that patients may occasionally use psychedelics. They feel that this is a personal choice and that the use is not problematic as long as it does not impact on the rest of the population. Health professionals made a distinction between recreational and therapeutic use of psychedelics, particularly with regard to risk reduction in a therapeutic setting. On the other hand, gaps in knowledge were highlighted, in particular for the effects and risks of psychedelics. Health professionals’ concerns were mainly related to material and organisational issues.

Conclusions: Health professionals made a clear distinction between recreational and therapeutic use of psychedelics. They recognise the importance of not only being informed, but also trained. On the other hand, caregivers are mainly concerned about material issues and not about moral conflicts. Thus, the reluctance is not only related to the negative effects that patients might suffer, but also to the potential repercussions on other patients due to work overload. Therefore, the introduction of this model of psychotherapy must take into account elements of the setting and organisation of the service and not only the therapeutic benefits.

Abstract ID: P03:22

Abstract type: Poster

Healthcare professionals perceived facilitators and barriers in using the Utrecht Symptom Diary - 4 Dimensional

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Background/aims: The Utrecht Symptom Diary - 4 Dimensional (USD-4D) supports healthcare professionals (HCPs) in identifying, monitoring, and discussing multidimensional symptoms and needs of patients in the palliative phase. Insight into the facilitators and barriers perceived by HCPs is essential for a successful implementation of the USD-4D. Therefore, this study aims to map HCPs’ perceived facilitators and barriers in using the USD-4D in clinical practice.

Methods: An explanatory mixed-methods study with a sequential design was conducted from August 2019 to September 2020 among HCPs working in palliative care. HCPs were eligible to participate if they cared for patients in the palliative phase. In the quantitative phase data were collected through a survey. Facilitators were items answered positively by ≥80% of participants. Barriers were items answered negatively by ≥20% of participants. These answers were elaborated upon in mixed composition focus groups in the qualitative phase. The Capacity-Opportunity-Motivation-Behavior (COM-B) model has been used to contextualize the perceived facilitators and barriers.

Results: 122 HCPs completed the survey: 95% women, mean age 48 years and 72% nurses. The USD-4D’s purpose and potential are perceived as facilitating its usage. Perceived barriers concern lack of knowledge and uncertainty about competences and attitude. Furthermore, HCPs put emphasis on having a ‘good conversation’, raising the threshold to invite patients for a conversation.

Conclusions: HCPs perceive both facilitators and barriers in using the USD-4D. Implementation strategies will have to focus on increasing knowledge and developing competencies to work with the USD-4D. Knowledge should be focused on the use of the USD-4D and in-depth exploration. Amelioration of conversational skills of HCPs is a precondition to provide appropriate care using the USD-4D.

Abstract ID: P03:23

Abstract type: Poster

Patients’ needs in using the Utrecht Symptom Diary - 4 Dimensional

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Background/aims: In palliative care, the Utrecht Symptom Diary – 4 Dimensional (USD-4D) supports identification, monitoring and discussion of multidimensional symptoms and care needs. Understanding what preconditions should be met for patients in the palliative phase is essential for a successful implementation. Therefore, this study maps what patients in hospice and homecare settings need to use the USD-4D.

Methods: Generic qualitative design with semi-structured interviews. Patients in the palliative phase were recruited purposefully within hospice and home care settings if they were ≥ 18 years old and in their last year of life. The latter was operationalized with the surprise question. Furthermore, patients had to be aware of their life-threatening condition, had to have completed the USD-4D at least once and be able to be interviewed for 15 – 45 minutes. The interviews were transcribed and thematically analyzed.

Results: 13 patients were included (7 men, age 44-83, 11 within hospice setting). Patients’ needs focused around four themes: setting goals, empowerment, unbiased atmosphere, and non-judgmental approach. Having a clear understanding of the USD-4D and what was done with its outcomes was a precondition for wanting to use it. Next, patients expressed the importance of being involved in deciding whether to use the USD-4D, rather than being told they should. Finally, patients wanted to think about the items in their own pace and way. HCPs should attune to their personality.

Conclusions: Patients appreciate being invited to complete the USD-4D, but do not want to feel obligated to do so. Inviting them and taking their

answers seriously is the foundation of supporting patient autonomy and personalized care. Perceived facilitators and barriers can be derived from the preconditions, which can be the foundation for implementation strategies focusing on healthcare professionals in daily practice.

Abstract ID: P03:24

Abstract type: Poster

Serious Illness Care Programme UK: A Qualitative Exploration of Patient and Clinician Experiences of Serious Illness Conversations

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Background/aims: Poor communication about end-of-life-issues, contributing to a lack of shared decision-making and care planning can be detrimental to the quality of life of seriously ill patients and their families. However, such conversations can be challenging. For example, clinicians often miss or avoid opportunities for these discussions, and patients/families view professionals as being too busy to talk. The Serious Illness Care Programme is a 'systems wide' complex intervention to improve communication, care planning and quality of life for patients with serious illness (SI). Pilot implementation in the UK reported positive preliminary results and recommended further research into the experiences of key 'actors' in these SI conversations.

Aim: A qualitative exploration of the lived experience of seriously ill patients and clinicians who have engaged in SI conversations.

Methods: A phenomenological approach was taken using one-to-one narrative style interviews with two participant groups:

- (1) patients with cancer and renal failure receiving dialysis with experience of the SI conversation;
- (2) oncology and nephrology consultants who facilitated the SI conversations.

Reflexive Thematic Analysis was used to identify patterns of meaning related to the experience of engaging in these conversations.

Results: Three themes were generated from patient and clinician interviews:

A different conversation: SI conversations were seen as important but also distinctly 'different' to those engaged in routine clinic appointments
Relatedness to death: the concept of death; the prospect of it, planning for it, and the patients proximity to it, framed patient and clinician experience of the conversation

Organisation, logistics and control: Infrastructure for the SI conversations was important; impacting patient understanding of the purpose, and consistency in access to the conversation.

Conclusions: SI conversations can be a significant event for patients and clinicians. Implications for practice and policy will be discussed.

Abstract ID: P03:23

Abstract type: Poster

Patients' needs in using the Utrecht Symptom Diary - 4 Dimensional

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Background/aims: In palliative care, the Utrecht Symptom Diary - 4 Dimensional (USD-4D) supports identification, monitoring and discussion of multidimensional symptoms and care needs. Understanding

what preconditions should be met for patients in the palliative phase is essential for a successful implementation. Therefore, this study maps what patients in hospice and homecare settings need to use the USD-4D. **Methods:** Generic qualitative design with semi-structured interviews. Patients in the palliative phase were recruited purposefully within hospice and home care settings if they were ≥ 18 years old and in their last year of life. The latter was operationalized with the surprise question. Furthermore, patients had to be aware of their life-threatening condition, had to have completed the USD-4D at least once and be able to be interviewed for 15 - 45 minutes. The interviews were transcribed and thematically analyzed.

Results: 13 patients were included (7 men, age 44-83, 11 within hospice setting). Patients' needs focused around four themes: setting goals, empowerment, unbiased atmosphere, and non-judgmental approach. Having a clear understanding of the USD-4D and what was done with its outcomes was a precondition for wanting to use it. Next, patients expressed the importance of being involved in deciding whether to use the USD-4D, rather than being told they should. Finally, patients wanted to think about the items in their own pace and way. HCPs should attune to their personality.

Conclusions: Patients appreciate being invited to complete the USD-4D, but do not want to feel obligated to do so. Inviting them and taking their answers seriously is the foundation of supporting patient autonomy and personalized care. Perceived facilitators and barriers can be derived from the preconditions, which can be the foundation for implementation strategies focusing on healthcare professionals in daily practice.

Abstract ID: P03:26

Abstract type: Poster

Palliative Care Outcomes Collaboration (PCOC) – Embedding the Symptom Assessment Scale (SAS)

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Background/aims: PCOC, an assessment and response framework, uses five validated assessment tools to identify and manage symptoms and problems experienced by PC patients. PCOC is reflective of all domains recommended by expert international consensus regarding PC outcome measures. While four of the five PCOC tools are clinician rated, the Symptom Assessment Scale (SAS), a patient-reported outcome measure (PROM) is ideally patient rated but has been validated for assessment by proxy. Successfully embedding PROMs in clinical practice offers opportunities to ensure care is driven by patient priorities and needs but can be difficult to achieve in practice.

Aim: Ensure the standardised introduction and utilisation of the SAS PROM and associated resources by all staff.

Methods: Further to ethical approval, baseline data and the impact of 6 Plan Do Study Act (PDSA) cycles were evaluated. An average of 6 patient questionnaires were completed per cycle to monitor impact of quality improvement initiatives, include, process maps, driver diagrams, audit, staff education and focus groups.

Results: Comparing percentages from cycle 1 to 6, patients who reported it was easy to score their distress increased from 40% to 80% they understood why they were being asked to score their distress increased from 20% to 100%

they were shown the SAS ruler, increased from 0% to 100% Percentage of patient rated scores increased from 69.3% in the month prior to project initiation to an average of 80.8% in the final month of project.

Conclusions: Systematic application of the model for improvement including iterative cycles of audit, patient feedback and discussion with

and education of staff were effective mechanisms to improve clinical practice. The majority of patients reported that using the SAS helped them feel more involved in their care.

Abstract ID: P03:27

Abstract type: Poster

From Research to 'Real Life': How to Adapt an Effective Intervention From a Clinical Trial to the Everyday Life in the Clinic

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Background/aims: The Herlev Hospital Empowerment of Relatives through More and Earlier information Supply (HERMES) intervention is a conversation between the informal caregiver and an oncology nurse in which 1) the caregiver's unmet needs for information are identified through a 14 item-instrument, and 2) the nurse provides the caregiver with the lacking information.

Our randomised controlled trial (n=199) showed that the intervention improves the caregivers' experiences of information, communication and attention from oncology health care professionals (HCPs).

While feasible in an RCT, adaptations to facilitate wider uptake in the healthcare system was needed.

We here report the first steps of an implementation project adapting the HERMES intervention to promote its uptake in the clinical everyday life for cancer patients in hospitals.

Methods: The adaptation process included several steps with input from various stakeholders: 1) nurses who had used the intervention identified barriers and solutions in discussions with the research group, 2) solutions were discussed in two focus group interviews with HCPs, 3) the solutions were implemented in collaboration with a software programmer and with feedback from a patient user panel and 4) the adapted intervention was tested by two HCPs and five caregivers.

Results: The following adaptations of the intervention were made: a) instead of administering the 14 information items on paper, a caregiver app for mobile phones was developed, b) instead of HCPs leading the intervention, the caregivers became responsible for using the app and showing their answers to the HCPs and c) instead of planned conversations, the discussion of the caregivers' answers could happen at any time.

Conclusions: We have succeeded in adapting the HERMES intervention in a way that has preserved the essence of the intervention and have minimised the use of resources in the clinic. In the next steps, we will test the consequences of the adaptations on effect and feasibility.

Abstract ID: P03:28

Abstract type: Poster

Facilitators and barriers experienced by hospital clinicians in discussing values, wishes and needs of patients in the palliative phase: a mixed-methods systematic review

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Background/aims: Communication between hospital clinicians and patients in the palliative phase about their values, wishes and needs is essential to achieve appropriate palliative care. Aim: To explore the barriers and facilitators concerning communication with patients in de palliative phase about their values, wishes and needs as experienced or indicated by hospital clinicians.

Methods: A mixed-methods systematic review was conducted following the PALETTE-method and PRISMA-guidelines. Eight databases were searched without time-restrictions. Original articles were eligible if they focussed on 1) hospital clinicians and 2) barriers and facilitators to communication about values, wishes and needs of adult patients in the palliative phase. Two researchers independently selected articles and appraised the quality. Findings were synthesized using a convergent integrated approach following the Joanna Briggs Institute's guidelines.

Results: 2259 articles were identified. Preliminary results from the studies selected to date (N=23) show that the barriers and facilitators can be expressed in four synthesized findings:

- 1) Patient characteristics: lack of understanding of the disease and treatment or difficulty accepting the prognosis;
- 2) Clinician characteristics: lack of competence or experience;
- 3) Patient's social context: dealing with conflicting views or family tensions;
- 4) Organizational factors: a lack of time and privacy or unclear roles.

Most studies focussed on decision making about medical treatment in the physical dimension, often near the end of life.

Conclusions: Hospital clinicians indicate several barriers and facilitators to discuss the values, wishes and needs with patients in the palliative phase. A structured approach to explore and monitor the patients' values, wishes and needs in all four dimensions and throughout the entire palliative phase would be beneficial to ameliorate appropriate palliative care.

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Abstract ID: P03:30

Abstract type: Poster

Interest of Older People to Attend Information Meetings about Care at the End-of-Life is Associated with Knowledge of Palliative Care and Worries

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Background/aims: A way to inform older people about end-of-life care, is to organise information meetings. We looked at differences between persons who would or would not visit a meeting regarding knowledge on palliative care and worries.

Methods: In September 2020 a questionnaire was sent to 1,333 members of the LISS-panel (>= 65 years); response was 92.5% (n=1,234). Differences between persons who would attend a meeting or not are analysed with logistic regression.

Results: If they would receive an invitation this week, 33% of older persons would attend a meeting. People who want to attend say they are (quite) sure they know what the terms palliative (53% vs 44%) and terminal (66% vs 58%) care mean and more often say palliative care is not only for patients with cancer (80% vs 71%) compared to people not wanting to attend a meeting. They indicated less often not knowing whether the statement 'palliative care is only for persons who have a few weeks left to live' is true or false (18% vs 25%), both the wrong and the right answer are given more often by them compared to people not wanting to attend a meeting. There were no differences for other knowledge questions (on settings in which palliative care is provided and the combination with life prolonging care).

People who want to attend a meeting worry more often about: their loved ones (16% vs 1%), loss of self-direction (10% vs 7%), death (9% vs 6%), loss of the ability to care for themselves physically (9% vs 5%), not accepting things as they are (7% vs 4%), and physicians not taking their wishes into account (6% vs 4%), compared to people not wanting to attend a meeting. **Conclusions:** Older persons who (by their own account) know the terms palliative and terminal care, are more interested in attending a meeting. As their knowledge of palliative care appears to be limited, meetings can have added value in learning more about palliative care. In advertising and during the meetings attention should be paid to topics older persons worry about.

Abstract ID: P03:31

Abstract type: Poster

Knowledge of End-of-Life Wishes by Physicians and Family Caregivers in Cancer Patients

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Background/aims: To describe communication regarding cancer patient's end-of-life (EoL) wishes by physicians and family caregivers.

Methods: An online questionnaire and telephone-based surveys were performed with physicians and family caregivers respectively in three teaching hospitals in Colombia which had been involved in the EoL care of cancer patients.

Results: For 138 deceased patients we obtained responses from physicians and family caregivers. In 32% physicians reported they spoke to the caregiver and in 17% with the patient regarding EoL decisions. In most cases lacking a conversation, physicians indicated the treatment option was "clearly the best for the patient" or that it was "not necessary to discuss treatment with the patient".

Twenty-six percent of the caregivers indicated that someone from the medical team spoke with the patient about treatment, and in 67% who had a conversation, caregivers felt that the provided information was unclear or incomplete. Physicians and family caregivers were aware if the patient had any advance care directive in 6% and 26% of cases, respectively, with low absolute agreement (34%).

Conclusions: There is a lack of open conversation regarding EoL in patients with advanced cancer with their physicians and family caregivers in Colombia. Communication strategies are urgently needed.

Abstract ID: P03:32

Abstract type: Poster

Increasing Advance Care Planning Engagement with Older People Living with Frailty

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Background/aims: Advance care planning (ACP) supports person-centred end-of-life care by enabling individuals to articulate their end-of-life preferences. Frail elders' vulnerability to sudden deterioration makes

ACP particularly relevant but engagement is uncommon. This study aimed to develop an intervention to increase health and social care professionals' (professionals) engagement of cognitively able, domestic-dwelling frail elders (frail elders) with ACP.

Methods: Intervention development was guided by the Medical Research Council framework for complex interventions and the Behaviour Change Wheel. Barriers and enablers to ACP were established through a systematic integrative review (papers n=42), e-Delphi survey (professionals n=73), and semi-structured interviews (frail elders n=10 family members n=8). A conceptual model, developed from the review, underpinned data collection. Data were thematically analysed, synthesised and triangulated to identify behaviours that needed to change and design the intervention. A refinement exercise was conducted. Professionals (n=26) undertook the intervention, tested it in practice, and provided feedback through pre- and post-intervention surveys and focus groups.

Results: The prototype intervention is a 3.5-hour educational skills session for professionals supported by a toolkit. The intervention focuses on frail elders' experience of ACP and its relevance to them, and strategies to encourage ACP engagement including preparing frail elders for ACP, early engagement, and emphasising living well now and shared decision-making. Refinement exercise feedback suggests the intervention helped participants think differently about ACP and increased their motivation to engage frail elders.

Conclusions: To our knowledge this is the first behaviour change intervention to focus on supporting professionals to engage frail elders with ACP. Further stakeholder evaluation and refinement is required; however, feedback suggests the intervention is acceptable, engaging and clinically valuable.

Abstract ID: P03:33

Abstract type: Poster

The Surprise Question in Older Hospitalized Patients: To Use or Not to Use?

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Background/aims: Studies on the validity of the Surprise Question (SQ) in older hospitalized patients are scarce.

Aim was to establish the predictive validity of the SQ in older hospitalized patients. Secondary aims were whether the SQ performed different between physicians and nurses, between patients >80 and <80 years, and its predictive validity by combining answers of physicians and nurses and adding age.

Methods: *Design:* Prospective observational single-center cohort study. *Data collection:* Of all patients >60 years, admitted to the department of internal medicine of a Dutch university hospital, sex, age, one-year mortality, and the SQ was assessed.

Analysis: Chi-square test, calculation of positive (PPV) and negative (NPV) predicted values, sensitivity and specificity, and logistic regression (LR) were performed. The performance of the LR models was assessed by the area under the receiver operating characteristic curve (AUC).

Results: Of the 308 included patients 117 (38%) deceased within 12 months after SQ assessment. Physicians answered the SQ with 'no' in 211 (68%) patients, nurses in 226 (74%) patients. The SQ responses differed significantly between physicians and nurses ($p < 0.001$). PPV of

physicians and nurses were 49.3% and 46.5% respectively, NPV 86.6% and 87.5%. Sensitivity for physicians was 88.9%, for nurses 91.3%, and specificity 44.0% and 36.7%, respectively. LR analyses revealed that the SQ was a significant predictor for one-year mortality, for physicians (odds ratio 6.28, 95% confidence interval 3.30-11.95) and nurses (6.07, 2.98-12.38). The AUC's were 0.66 for physicians and 0.65 for nurses. By combining the answers of physicians and nurses and adding age, the AUC increased to 0.71.

Conclusions: The SQ performs moderately in older hospitalized patients. Although SQ scores differed between physicians and nurses, overall performance was rather similar. However, combining answers of physicians and nurses and adding age seems promising.

Abstract ID: P03:34

Abstract type: Poster

Mechanisms and Contextual Influences on the Implementation of Advance Care Planning for Older People in Long-Term Care Facilities: A Realist Review

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Background/aims: Older people in long-term care facilities (LTCFs) face clinical uncertainty and unpredictable decline. Advance care planning (ACP) enables older people to identify preferences and wishes for future treatment and care before any loss of capacity. However, it is unclear how, why and under what circumstances the implementation of ACP for older people can be normalised into routine practice within LTCFs. We aimed to identify contextual factors and mechanisms that underpin the implementation of ACP for older people in LTCFs.

Methods: Consistent with realist review methodology, we developed the initial programme theory by scoping reviews, engaging Western and Asian stakeholders and utilising Normalisation Process Theory. MEDLINE, EMBASE, CINAHL, PsycINFO, Web of Science, and Scopus were subsequently searched 01/01/1990 to 11/06/2021. Inductive and deductive coding was used to generate context-mechanism-outcome configurations (CMOCs), which were iteratively tested to refine the programme theory.

Results: 5459 records were identified, and 48 retained for final synthesis. Seven CMOCs were identified: carry out sensitive conversation gradually; wait for 'a window of opportunity'; deliver sustainable and available training; build a collaborative and multidisciplinary network; conduct collaborative negotiation; secure active leadership buy-in; and keep conversation and documentation on track. A logic model was developed to conceptualise the causal pathways between the contexts, mechanisms, and outcomes.

Conclusions: NPT facilitates a theoretically informed explanation of mechanisms behind how individual and collective interactions within LTCFs impact the implementation of ACP. Keys to normalising ACP were older people, family and staff make sense of the values of ACP, a collaborative approach and active leadership engagement, available training resources within organisations, and reflections on the utility of ACP. Further researches are needed to understand the implementation of ACP at a broader system level.

Abstract ID: P03:35

Abstract type: Poster

Talking About Meaning and Loss With Relatives of Persons With Dementia: An Ethnographic Study in the Nursing Home

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Background/aims: Being confronted with a diagnosis of dementia often raises questions about the future. Studies have shown that patients ask healthcare professionals more questions relevant to their personal situation if provided with a question prompt list (QPL). We developed a QPL with information and sample questions for persons with dementia and their relatives includes a heading about meaning and loss. This topic is easily missed in conversations with healthcare professionals.

Aims: To evaluate the QPL in enhancing conversations between professionals and relatives about meaning and loss in the context of advance care planning in dementia.

Methods: Qualitative ethnographic study (January-September 2021) with 13 open interviews with relatives and healthcare professionals on 6 wards of a nursing home in the Netherlands. The professionals received training in using the QPL. Thematic analysis by Braun & Clarke was chosen for the interviews which were transcribed verbatim, and the researchers discussed memos of observations which were analysed along with the interviews.

Results: Preliminary analyses indicate that the interviewees all appreciated the information provided in the QPL. However, there was a mismatch between the preferred focus of the conversations as the professionals wished to talk about care goals and the completion of the care plan while such focus was not helpful in conversations about meaning and loss. In contrast, the relatives wished to (first) address practical matters such as the environment in the nursing home, the laundry and food. Further, the QPL could increase confidence in starting conversations about meaning and loss, but the professionals felt a need for more training.

Conclusions: Themes will be presented after full analyses. A QPL can be helpful in having a conversation about meaning and loss, but nursing staff need dedicated time and substantial training.

Abstract ID: P03:36

Abstract type: Poster

Change in Advance Care Plans in Nursing Homes When People With Dementia Experience Pneumonia: Secondary Data Analysis of RCT Data

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Background/aims: Advance care planning helps in providing future care in line with people's wishes. This requires advance care plans to be dynamic, to address changes in wishes if preferences or health change.

Aims: To explore changes in advance care plans of nursing home residents with dementia after being diagnosed with pneumonia.

Methods: Secondary data analysis of physician-reported PneuMonitor trial data collected between January 2012 and May 2015 in 32 nursing homes across the Netherlands, including 429 residents with dementia who developed a pneumonia. We compared advance care plans before and after the first pneumonia episode during the trial. Generalized linear mixed models were used to explore associations of changes in advance care plans with the person most influential in decision making, demographics and indicators of disease progression.

Results: After the first pneumonia episode, care goals were revised in 15.9% and treatment plans in 20.0% of residents. We did not find significant associations with changes in care goals after a pneumonia. However, changes in treatment decisions were more likely for residents who were more severely ill (Odds Ratio 1.5, 95% confidence interval 1.2 - 1.9) and those estimated to live less than 3 months (Odds Ratio 3.3, 95% confidence interval 1.9 - 5.8).

Conclusions: Although advance care planning is common nursing home practice, there are limited changes in these arrangements after pneumonia.

This suggests stability of preferences or limited dynamics in the process of advance care planning.

Funding: The PneuMonitor trial is supported by the Netherlands Organisation for Scientific Research (NWO), Innovational Research Incentives Scheme, career award to JTvdS (grant number Vidi 91711339). The analyses are supported by the Netherlands Organisation for Health Research and Development (ZonMw) program Memorabel grant number 733051084 under the aegis of the EU Joint Programme - Neurodegenerative Disease Research (JPND) - www.jpnd.eu.

Abstract ID: P03:37

Abstract type: Poster

Family Involvement in Advance Care Planning for People Living With Advanced Cancer: A Systematic Mixed-Methods Review

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Background/aims: Advance care planning (ACP) is important for people with advanced cancer to align their treatment and care with their preferences when they lose mental capacity. Family involvement in ACP is key to achieving goal-concordant care since they often become surrogate decision-makers. This review aims to examine components, contexts, effects and linkages with intended outcomes of involving family members in ACP.

Methods: A mixed-methods systematic review was conducted. Primary quantitative and qualitative research were identified using Medline, Embase, PsycINFO and CINAHL from inception to September 2020. The search strategy included terms regarding ACP, family, cancer and end-of-life. Quality appraisal was performed with 'QualSyst'. Quantitative and qualitative data were extracted. Quantitative data were transformed into qualitative data and synthesised using thematic synthesis leading to a logic model.

Results: Fourteen articles were included. The synthesis identified multiple perceptions of individuals and family members concerning family involvement in ACP including (i) the variable value family members attributed to ACP; (ii) concerns about their readiness to engage in the process; (iii) contextual issues associated with decision-making for example social norms, which contribute to components for family-integrated ACP intervention. The resulting logic model includes (i) addressing family members' concerns and emotions and (ii) facilitating communication between individuals and family members as distinct from healthcare professionals engaging with individuals and family members.

Conclusions: Whilst the number of studies concerning family involvement in ACP were limited this review provides a comprehensive understanding of family involvement in ACP and informs ACP implementation in clinical practice. Future research must focus on family integration and exploration of stakeholders' perceptions to identify additional components and linkages between them within family-integrated ACP.

Abstract ID: P03:38

Abstract type: Poster

Developing an Advance Care Planning Website for People With Dementia and Their Family Caregivers: Results of a Focus Group Study on User Perspectives

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Background/aims: To support advance care planning (ACP) among people with dementia and their families, the use of interactive ACP websites

seems promising. However, no currently available websites are specifically designed for or with people with dementia and their family caregivers. The aim of this study is to assess the needs and preferences of persons with dementia, family carers and healthcare professionals regarding the content and functionalities of a website to support ACP, and to explore potential barriers and facilitators for finding and using such a website.

Methods: A focus group study with people with dementia, family carers, and healthcare professionals, conducted online, using a semi-structured topic guide. To analyse the data, we used a combination of deductive and inductive coding approaches to define themes.

Results: We conducted one focus group with people with dementia (n=3), four with family carers (total n=18), and three with health care professionals (total n=17). Between the participants groups there were overlapping needs, preferences and perceived barriers and facilitators. Regarding the content of the ACP website, participants valued information on ACP and on dementia, as well as guidance on how to start and conduct an ACP conversation. Information on ACP would ideally be presented using testimonials. Participants also considered a text-to-speech option and a print option as important functionalities that would increase the accessibility of the website. A lack of computer literacy was found to be the most important barrier for finding and using the website. To find the website, participants suggested it should be promoted via healthcare organizations and healthcare professionals.

Conclusions: The ACP website should focus on providing ACP information and supporting ACP communication. The findings will be used in the development of the ACP website for people with dementia and their family caregivers.

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Abstract ID: P03:39

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/aims: ConCure-SM is a multi-phased, mixed-methods research project on developing and testing an advance care planning (ACP) intervention for people with progressive multiple sclerosis (pwPMS). Here we present on the users' assessment and revision of the booklet to be used in the ACP conversation (Project Phase 1).

Methods: An inter-disciplinary panel translated/adapted to the Italian legislation and to the MS context a booklet developed by the National ACP programme for New Zealand (<https://www.myacp.org.nz>). The provisional booklet was debriefed via cognitive interviews with pwPMS and their significant others (SOs) and a focus group (FG) with HPs. We analysed the interviews using the framework method, and the FG using thematic analysis. Based on the findings the provisional booklet was revised. 3 well-informative participants (2 pwPMS and 1 SO) took part in a second round of interviews to validate booklet revisions.

Results: Between September-January 2021 we held 13 online interviews which lasted 36-80'. Participants were 10 pwPMS and 3 SOs. Twelve HPs

from 3 centers participated in the online FGM (7 neurologists, 3 psychologists, 1 nurse and 1 physiotherapist), which lasted 105". Three overarching themes emerged from the interviews: comprehensibility/clarity; content acceptability/emotional impact; suggestions for improvement. Participants found the booklet useful and informative, though emotionally taxing. The FG was well participated, with few experiential data on ACP. Two themes emerged: content importance/clarity; challenges to ACP implementation (HP preparedness; finding the right point to start this conversation; concurrent obligations at the center). The second round interviews confirmed the revised booklet was improved in clarity of contents and layout.

Conclusions: Cognitive debriefing was key to refine the ConCure-SM booklet. Findings corroborated the use of the booklet within ACP conversation, and the challenge of appraising it as a stand-alone tool.

Abstract ID: P03:40

Abstract type: Poster

Engagement in Advance Care Planning (ACP) Of Patients With Chronic, Life-Limiting Illness in the General Practice Setting: Baseline Findings From a Cluster-Randomized Controlled Trial

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Background/aims: While engagement in ACP of people with life-limiting illness may be influenced by demographic and clinical characteristics or communication skills of general practitioners (GPs), exploration of these associations are limited. This study aims to assess whether patient characteristics, ACP contemplation and advance directive completion, and patient-perceived GP communication skills are associated with ACP engagement.

Methods: Baseline data from a cluster-randomized controlled trial in patients with chronic, life-limiting illness (n=95). Patients completed questionnaires for demographic and clinical characteristics, completion of advance directives (AD) and ACP contemplation, and perception of the GP's ACP information provision and listening to ACP topics (10-point Likert). Engagement was measured using the 15-item ACP Engagement Survey, with self-efficacy and readiness subscales (5-point Likert). Linear mixed models tested associations with engagement.

Results: Patient demographic and clinical characteristics were not associated with engagement. Patients who had completed an AD had higher engagement ($p < .001$), as did patients with a high rating of ACP contemplation ($p = .006$). Engagement was higher in patients who perceived that their GP listened to what is important to them regarding future care ($p = .031$), and what their worries are regarding future health ($p = .018$). Patients who perceived higher provision of information about ACP by their GP had greater self-efficacy only ($p = .034$).

Conclusions: Patient characteristics were not associated with engagement, but perceived GP communication, i.e., listening to what the patient finds important regarding future care and worries about future health, was. This highlights the importance of offering ACP to patients with life-limiting illness as standard practice. Two-way communication where the GP provides information and listens to the patient regarding their future health and care, are important to leverage engagement.

Funding: Research Foundation Flanders (FWO)

Abstract ID: P03:42

Abstract type: Poster

Perceptions of End-of-Life Care by Treating Physicians in Cancer Patients

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Background/aims: Aging and the increase in life expectancy have led to an increase in chronic and degenerative diseases, including cancer. Medical decisions during the end-of-life (EoL) process directly influence the experience of the patient and family. These decisions include choices in treatment and practices related to dying such as: not starting or stopping specific treatments for the disease, emphasizing the management of pain and other symptoms of advanced disease, or the use or not of palliative sedation.

Aims: To describe the medical perceptions of EoL care in cancer patients in medium and high complexity hospitals in Colombia.

Methods: Cross-sectional study carried out in the years 2019 and 2020 in three Colombian hospitals. We used a self-administered questionnaire applied to general practitioners or specialists to measure the perception of EoL care given to cancer patients who were at the EoL or close to it.

Results: We identified 341 deceased patients and 261 responses were obtained from their treating physicians (response rate of 77%). The median time between death and response to the questionnaire was 9 days. Most patients (73%) died within a hospital and 17% at home. Most physicians (70%) consider that death was not a consequence of medical interventions and 85% classified the therapeutic strategies as palliative care approaches. The prevalence of peacefulness of the physicians with the medical care provided during the EoL process was 87%. The possibility of accelerating the EoL as a result of interventions or no interventions was discussed with 42% of the patients and 61% of their relatives by treating physicians.

Conclusions: There is great medical interest in the EoL phase of patients and avoiding unnecessary interventions. EoL was perceived with peacefulness by most treating physicians in cancer patients. A lack of good communication with the patient or their family members during this period can be an area of great improvement.

Funding: This study was financed by Colciencias, in the framework of the "777-2017 Convocatoria para proyectos de ciencia, tecnología e innovación en Salud 2017", project CT-826-2018 - Decisiones médicas al final de la vida en pacientes oncológicos en Colombia". The funding source had no impact on design, analysis or interpretation of the data.

Abstract ID: P03:43

Abstract type: Poster

Iatrogenic Suffering at the End of Life: An Ethnographic Study

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Background/aims: A significant proportion of older people in the United Kingdom (UK) die in hospital, with variable quality of care. A palliative approach, which involves recognising and alleviating suffering, might lead to improved quality of care. Yet suffering is an intangible and contested phenomenon and little is known about people's actual experiences of suffering in this clinical setting. Further, it has been argued that an acute hospital setting is not well equipped to support dying well.

Aim: To examine the context of end-of-life care for older people in an acute hospital setting, particularly focusing on the experience of suffering.

Methods: Design: An observational study was conducted guided by the principles of sensory ethnography, within an interpretivist framework. Data analysis was inductive and iterative. Reflexive analysis included observations and inferences from a participant-observer perspective.

Over a period of three months in 2016, 186 hours of observations were carried out.

Settings / Participants: The study was carried out on a 30-bedded acute older peoples' hospital ward in the UK. Participants included 11 patients and 33 members of staff and visitors.

Results: Patient suffering was influenced by a range of factors. Delays in recognising and acknowledging dying often led to treatments that were burdensome or futile, exacerbating patient suffering. Environmental factors in the physical clinical setting also exacerbated suffering. Finally, aspects of interpersonal interactions were observed to adversely affect patient experience.

Conclusions: Acute care for older people in hospital was shaped by an overarching ideology of rescue which predicted and dictated the process of care. Findings demonstrated that suffering was not restricted to the direct experiences of life-limiting illness but was also associated with the experience of receiving care in an acute hospital setting. Avoiding or minimising iatrogenic suffering is an essential component of compassionate care.

Abstract ID: P03:44

Abstract type: Poster

Healthcare Professionals and Family Caregivers' Experiences of Using a Medication Kit for Symptom Management at the End of Life – A Literature Review

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Background/aims: In community end-of-life care, a scheme has been introduced where doctors can prescribe a 'kit' of anticipatory medications to ensure timely symptom relief.

The aim was to investigate how healthcare professionals and family caregivers experience using the medication kit, to identify factors to improve practice.

Methods: Systematic literature searches in PubMed and SweMed + for the period January 2000-July 2021. Articles presenting experiences from healthcare professionals and family caregivers related to the use of a physical medication kit for dying adults outside hospitals were included.

Results: Of 125 identified articles, 15 met the inclusion criteria, most of them qualitative interview studies. The findings show that the medication kit is useful for planning end-of-life care, clarifies treatment focus, provides security, facilitates conversations, is cost effective and helps reduce hospital admissions. Good communication and cooperation both between healthcare professionals, and with patients/relatives, as well as clear frameworks for use, ensure safe and appropriate use. Barriers for use are challenges with timing, especially in chronic conditions, uncertainties regarding prescriptions and distribution of responsibility, lack of proximity to colleagues, lack of training and confidence in assessments and limited access to equipment/medications. Risk factors are safe storage and possible drug abuse, which the prescribing doctor stands responsible for. Drug wastage was a recurring negative comment.

Conclusions: The medication kit is seen as a useful and important tool that enables timely symptom management and provides security at the end of life. The provision of a standardized kit with consistent content and instructions for use could facilitate communication and create continuity of care. Further research should address how the medication kit can be made available to everyone regardless of diagnosis and the experiences and attitudes of patients and relatives.

Abstract ID: P03:45

Abstract type: Poster

Dying in Hospitals – Optimization of Care in the Dying Phase (StiK-OV): Results of an Online Survey

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Background/aims: Hospitals are the most frequent place of death in Germany (47%) but also the least preferred one – for both patients and relatives. The project "StiK-OV" aims to optimize care for dying patients in hospitals using a bottom-up approach. Therefore specific measures on non-palliative wards at two university hospitals will be implemented and evaluated. In the first project phase, the current state of non-specialist inpatient care in the dying phase was assessed.

Methods: Online survey with national health care professionals in the field of care in the dying phase. The survey consisted of seven open-ended questions on important issues, facilitators, barriers and needs for improvement regarding the care for patients dying in hospitals as well as COVID-19 pandemic specifics. Qualitative data was analyzed thematically.

Results: Of 67 participants, 66% worked in clinical practice, 34% in managerial positions. We identified five relevant topics of care in the dying phase: involvement of relatives; symptom control; patient-centeredness; professional competencies; as well as time, space and human resources. Participants aimed to uphold patient-centeredness as a priority in the dying phase despite reporting needs for improvement in all topics: "Everything that is good for the patient is allowed." This contrasts with the experience during the pandemic, when involvement of relatives and patient-centeredness were hard to maintain due to visiting restrictions and high workload – leading to patient isolation and dying in loneliness.

Conclusions: The survey revealed common topics on care in the dying phase from the perspective of health professionals to be targeted by ward-specific measures. Difficulties due to the pandemic have to be considered for optimal care in the dying phase under exceptional circumstances. The results can help to develop and implement context-specific measures to improve quality of hospital care during the dying phase.

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Abstract ID: P03:46

Abstract type: Poster

Quality of Death in Terminally Ill Patients With Cancer and the Institutional Prevalence of Urinary Catheterization at Palliative Care Units

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Background/aims: The effects of urinary catheterization on the quality of life and quality of dying and death in patients with cancer have not yet been verified. Such an evaluation is needed to address the wide variation in the institutional prevalence of urinary catheterization in patients with cancer at palliative care units. This study aims to compare the quality of death (QoD) in terminally ill patients with cancer among institutions based on the prevalence of urinary catheterization at palliative care units.

Methods: This study was a secondary analysis of a multicenter, prospective cohort study, the East-Asian collaborative cross-cultural Study to Elucidate the Dying process (EASED). The study enrolled consecutive terminally ill patients with cancer admitted to palliative care units between January and December 2017. The patients in the evaluated institutions were equally classified into three categories according to the institutional prevalence of urinary catheterization: low, moderate, and high. QoD was evaluated at death using the Good Death Scale (GDS).

Results: Overall, 1,212 patients in 21 palliative care units were classified into the three institutional catheterization prevalence groups. The prevalence of urinary catheterization ranged from 0.0%–25.0%, 26.2%–34.4%, and 34.9%–55.4% in the low, moderate, and high prevalence groups, respectively. Only patients whose GDS scores could be evaluated at discharge ($n = 896$) were included in the analysis. The mean (standard deviation) total GDS score was 11.52 (2.49) for the low prevalence group, 12.11 (2.38) for the moderate prevalence group, and 12.07 (2.59) for the high prevalence group. In multivariate analysis, patients in both the moderate and high prevalence groups had higher total GDS scores than those in the low prevalence group ($p = 0.031$ and $p = 0.018$, respectively).

Conclusions: This study suggests that terminally ill patients with cancer at palliative care units in institutions with a low prevalence of urinary catheterization have a lower QoD.

Abstract ID: P03:47

Abstract type: Poster

Determinants for Tailoring and Implementation of Question Prompt Sheets in the Last Year of Life

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Background/aims: Question prompt sheets (QPS) are used to initiate discussion between patients and health care professionals (HCPs). Patients are encouraged to take part in health care decisions so that information deficits can be reduced. Although QPS are perceived as useful, they are rarely used in health care. Aims: Generating a QPS for hospitalised patients in their last year of life by identifying its determinants for tailoring and implementation

Methods: A first draft of the QPS was developed based on the German patient guideline 'Palliative Medicine' [1] and tailored by 10 guided interviews with patient representatives and HCPs. Determinants of

implementation were discussed. The evaluation was based on content analysis.

Results: Using the QPS in communication with patients in their last year of life was seen as helpful by the interviewees. The QPS was believed to encourage patients to ask questions and actively seek information. Interviewees described determinants like emotional factors, accessibility and amount of information.

Personal factors such as acceptance and self-efficacy, as well as cultural differences and individual counselling with sufficient time for preparation were mentioned as decisive aspects for the implementation of QPS.

Conclusions: Using QPS in communication with patients in their last year of life is seen as support for patient communication. Some determinants need to be considered in tailoring, e.g., accessibility by using large fonts and simple language. In addition, patients should be encouraged by HCPs to ask questions supporting open communication.

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Abstract ID: P03:48

Abstract type: Poster

Identifying Frailty in a Community of Housebound Patients and Defining Their Specific Needs in Terms of Palliative Care

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Background/aims: The early introduction of palliative care can have a positive impact on the quality of life of patients suffering from life limiting diseases. However, the palliative care needs of elderly, frail, housebound patients are still mostly unknown, as is the impact of frailty on the importance of these needs.

Methods: We conducted a cross-sectional observational study of patients that were ≥ 65 years old, housebound, followed by a geriatric community unit of the Geneva University Hospitals.

Results: 71 patients completed the study. Most patients were female (56.9%) and mean age(SD) was 81.1(± 7.9). Edmonton Frail Scale at entrance identified patients as being mostly vulnerable (37%) and mildly frail (31.5%). The Edmonton Symptom Assessment Scale mean(SD) score was higher in mild, moderate and severely frail patients as opposed to vulnerable patients for tiredness (3.88 ± 3.16 vs 2.07 ± 2.73 , $p=0.016$), drowsiness (2.45 ± 2.37 vs 1.15 ± 1.41 , $p=0.0196$), loss of appetite (2.20 ± 2.82 vs 0.70 ± 1.64 , $p=0.0124$) and feeling of wellbeing (3.73 ± 2.21 vs 2.39 ± 2.60 $p=0.0132$). There was no difference in spiritual well-being, measured with the spiritual scale subgroup of the Functional Assessment of the Chronic Illness Therapy-Spiritual Well-Being scale (FACIT-sp), between frail and non-frail patients. The mean score was low at 23.58 ± 7.30 on a scale of 0 to 48. Kaplan-Meier survival estimate within one-year did not differ between patients considered vulnerable or mildly frail as opposed to moderate to severely frail. Caregivers were mainly spouses (45%) and daughters (27.5%) with a mean(SD) age of $70.7 (\pm 13.6)$. The overall burden on the caregiver measured by the MINI-ZARIT was low (2.12 ± 1.49).

Conclusions: Older, fragile, housebound patients have specific needs that increase with the level of frailty and should guide future palliative care provision for this population.

Abstract ID: P03:49

Abstract type: Poster

Spanish Patients' and Professionals' Experiences With Wish to Die: Main Themes in a Qualitative Analysis

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Background/aims: The experience of wish to die has been broadly studied. However, in Spain, there is no qualitative research regarding the experiences of patients who wish to die and the experiences of professionals who take care of them. Both experiences need to be deeply understood. This project aimed 1) to explore in depth the experiences of patients who wish to die and 2) to know the experiences of health professionals who care for these patients.

Methods: A qualitative study with a hermeneutic-phenomenological approach was designed. Data was collected in three different palliative care services and consists in semi-structured interviews. Inpatients and outpatients attended by palliative care teams and professionals were interviewed.

Results: 14 patients with a wish to die and 18 palliative care professionals were interviewed. The interviews lasted between 20 to 60 min. Preliminary analysis shows that patients when referring to the wish to die mention two different themes: a) Loss; having lost something that was essential for them and b) Meaning, as a connection with life and wish to continue in it. Professionals when referring about the care of patients with this experience mention: a) Security, as the state of being free of judgement that is offered to the patient experiencing WTD and b) Search, as professional and personal search for trying to help the patient handling this situation.

Conclusions: Patients experiencing a wish to die have perceived the loss of different aspects that were important for them which contributes on experiencing a WTD. Professionals try to create a safe space that helps the patient express their experiences while looking for different approaches.

Abstract ID: P03:50

Abstract type: Poster

Enhancing Palliative Care Engagement in Indian Intensive Care Units Using a Theory of Change Framework

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Background/aims: Integrating palliative care within intensive care units (ICUs) can facilitate 'good death'. In India, effective integration is lacking, and thousands of patients discharge themselves from ICUs against medical advice due to doctors' reluctance to withdraw futile treatment and accompanying high costs for families.

Aim: To identify processes and potential impact of palliative care integration into Indian ICUs from the perspectives of critical care physicians.

Methods: A theory of change was used to map factors influencing ICU palliative care integration. Four virtual workshops and 15 team meetings were facilitated between April to August 2021. Fifteen stakeholders from Indian intensive and palliative care settings participated. Data included workshop discussion transcripts, online chatbox comments, and minutes of team meetings

Results: The theory of change map created had five potential outcomes, 12 preconditions, and 11 key interventions. The main driver was desire for better end-of-life care and good death. Measurable outcomes identified included: reductions in ICU deaths, discharge against medical advice, and number of inappropriate admissions; increased referrals to palliative care; and improved patient and family satisfaction. Preconditions included understanding legal issues and palliative care skill developments including communication. Key interventions included creating and educating staff about hospital palliative care policies; training ICU staff to identify, assess, and address palliative care needs; communication and documentation skills; strengthening ICU and palliative care collaboration; and raising public awareness on end-of-life care choices and advance care planning. Education was facilitated through an international webinar series.

Conclusions: Using a theory of change approach enabled identification of key drivers that might facilitate integration of palliative care services in Indian ICUs.

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Abstract ID: P03:51

Abstract type: Poster

Management of Acute Neurological Symptoms at End of Life in a Hospice Inpatient Setting

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Background/aims: Approximately 5-8% of patients with metastatic cancer experience acute neurological symptoms, which are typically a late complication. The cause is not always attributable to known tumour invasion or compression. Symptoms range from headache, confusion, and focal neurological deficits. This case report aims to demonstrate presentation and management of such a case during the last week of life.

Case Presentation: A 67 year old lady with a history of metastatic chondrosarcoma was a hospice inpatient for end of life (EOL) with a prognosis of weeks. She had deteriorated globally with new lower back pain associated with decreased power and sensation of lower limbs along with bladder and bowel dysfunction. In the last week of life, she presented with an acute onset of involuntary movements of predominantly left sided limbs associated with agitation and akathisia, however she remained conscious. There was no history of lumbar spine or cerebral metastases, recent medications associated with dystonic reactions or concern of infection.

Management: Neurological exam revealed a new finding of globally brisk reflexes. Symptoms were managed effectively with subcutaneous midazolam (30mg/24hours) and levomepromazine(25mg/24hours) and did not recur. This lady was bright and alert for a number of days and enjoyed quality time with her family. She deteriorated gradually and died peacefully surrounded by her family.

Discussion: Differentials include; leptomenigeal disease, paraneoplastic syndrome, and idiopathic dystonic reaction. Improved oncological treatments are leading to longer survival, however many treatments poorly penetrate the blood brain barrier and thus tumour cells may affect the nervous system. Thus management of such presentations is of increasing relevance in palliative care.

Conclusions: Advanced malignancy may cause a wide array of neurological symptoms. Appropriate treatment is guided by the goals of care, which during the terminal phase are comfort and dignity.

Abstract ID: P03:52

Abstract type: Poster

Effective Management of Refractory Status Epilepticus at End of Life

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Background/aims: Refractory status epilepticus (SE) is a life-threatening condition in which seizures do not respond to first or second line treatments. SE is uncommon at end of life (EOL) and guidelines for its management in the general population are not appropriate at EOL. This case demonstrates effective management of refractory SE at EOL.

Case Presentation: A 61 year old gentleman with metastatic melanoma and haemorrhagic transformation of known cerebral metastases was referred to palliative medicine for EOL care as he was deemed unfit for surgical resection. Prior to referral he developed SE despite being on regular intravenous (IV) leviteracetam (3g/24hrs). He was normoglycemic and there was no history of alcohol withdrawal. SE persisted despite multiple stat doses of subcutaneous (SC) midazolam(5mg) and IV lorazepam(1mg). On exam he was drowsy and in generalised convulsive SE.

Management: SE resolved with higher stat doses of midazolam (10mg SC) combined with phenobarbitone (200mg sc). Goals of care were discussed with his family and it was agreed to prioritise comfort. A 24 hour SC infusion of leviteracetam 3g/24hrs was commenced along with incremental titration of maintenance phenobarbitone to 800mg/24 hours and midazolam to 40mg/24hrs. This gentleman died peacefully 24 hours later surrounded by his family.

Discussion: Effective management of SE at EOL may require combinations of medications which are not recommended in general adult guidelines. Midazolam, levetiracetam and phenobarbitone can be given via 24 hour SC infusion and thus are used in preference to lorazepam and phenytoin. Advances in oncology treatments have increased survival in cancer patients along with incidence of brain metastases, which are associated with seizures. Thus management of SE is of particular relevance in palliative care.

Conclusions: Further research is required to establish evidence-based guidelines on effective management of refractory SE at EOL in order to minimise distress for patients and families.

Abstract ID: P03:53

Abstract type: Poster

References to Palliative Care and Linguistic-Discursive Framework in Spain's New Euthanasia Law

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Background/aims: Spain has become the sixth country in the world to regulate euthanasia practice through Organic Law 3/2021.

The objective is to examine the discourse used by the legislator to refer to palliative care and the context of end of life care.

Methods: Linguistic-discursive analysis of the law according to the argumentative framework and linguistic features (lexicon, syntax and implicatures), with special attention to references to palliative care.

Results: Argumentative premises have been identified. On the one hand, it is claimed that there is a sustained demand for euthanasia by today's society without providing evidence for it. Also, the law argues for the legal compatibility of euthanasia with the constitutional right to life, but this is not substantiated. Finally, the need to address the existence of society's new values is stated, without rigorously examining which are those values. On the other hand, the doctrine of the European Court of Human Rights is used as an argument of authority, while arguments or bills passed by national organisms are not cited. From a linguistic point of view, euphemisms are detected to refer to euthanasia ("aid in dying", "medical aid act"), lexical vagueness is introduced into technical discourse ("suffering. . . that could not have been mitigated otherwise") and designative subjectivities are identified ("regarded as acceptable", "unbearable for the sufferer", "prospect of improvement"). Palliative care appears in the text as an incidental appendix with no place for its exact definition. The term *palliative care* is identified with "indirect active euthanasia"; palliative aid is mentioned as a "possible action" or as a last resort to be presented in the deliberative process after the expression of the desire for hastened death.

Conclusions: The new Spanish euthanasia law presents argumentative inconsistencies and problematic linguistic-discursive choices. The identified references to palliative care are either unspecified or inappropriate.

Abstract ID: P03:54

Abstract type: Poster

Estimating the Size and Describing the Characteristics of Family Caregiving for People With Serious Illness: A Population-Based Survey

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Background/aims: Family caregivers play a vital role in care for people with serious illness. Reliable population-level information on family caregiving is scarce.

Methods: The aim of this study is to describe the numbers, characteristics, and experiences of family caregivers of people with serious illness using population-based data. We performed a secondary analysis of the cross-sectional population-based 19th Social-Cultural Changes survey. A random sample of 2,581 Dutch-speaking people aged 18 to 95, living in Flanders or Brussels, were surveyed between March and July 2014 using a stratified two-step sample. Differences between groups are described using Pearson chi-square tests and analysis of variance.

Results: Response rate was 59% (1,515/2,581). Over a 12-month period, 7.6% of participants had provided family care for someone with serious illness. They were most often aged 55-74 (36.0%), women (57.9%), worked full-time (42.3%); 31.8% provided at least ten hours of family care each week. Family caregivers of people with serious illness, compared with family caregivers of people with other conditions or disabilities, provided more medical and nursing care (33.3% vs 22.5%, p=0.027), and experienced a higher burden of family caregiving (p=0.038) but a similarly high meaningfulness of family caregiving.

Conclusions: A considerable part of the adult working population provides family care for someone with serious illness. While family caregiving for someone with serious illness shows similarities with family caregiving for people with other conditions in terms of caregiver characteristics, the impact of caregiving on work-life balance and meaningfulness, it is also associated with increased burden.

Abstract ID: P03:55

Abstract type: Poster

Mapping Palliative Care Research in Intensive Care Units in Lower- And Middle-Income Countries: A Scoping Review

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Background/aims: Although integrating palliative care in intensive care units (ICUs) is challenging, it promotes decision-making, appropriate treatment, care at end of life, and family satisfaction. Less is known about whether these benefits extend worldwide.

Aim: To understand the breadth and scope of research on the provision of palliative care within ICUs in low- and middle-income countries

Methods: Using a scoping review design, nine databases were searched for empirical literature published in English on palliative care in adult and pediatric ICUs in an LMIC setting from 01/01/1990 to 31/05/2021. Two reviewers independently checked all the search results using a web-based biomedical systematic review software, extracted textual data, which was analyzed and represented as themes and subthemes.

Results: Out of 6834 initial hits, 31 studies were included in the review. Most were from India (48%), in mixed adult and pediatric ICU settings (32%), and published between 2015-2020 (42%). Major areas of research focus were: perspectives of and attitude towards end-of-life care and futility; facilitators and barriers of end-of-life care in ICUs which included costs, socio-cultural and religious factors, legal issues, legislative and procedural ambiguities; knowledge and skills in palliative care; pathways for decision-making regarding end-of-life care; frameworks for palliative care delivery in ICUs; and outcomes of palliative care delivery. All studies in this review were non-experimental and none explored symptom management, emotional issues, or patient and family caregiver perspectives.

Conclusions: Publication trends demonstrate a slow rise in palliative care research in LMIC ICUs. Knowledge of integration barriers identified in surveys and qualitative studies might enable the development of contextual ICU-specific palliative care interventions and their outcomes.

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Abstract ID: P03:56

Abstract type: Poster

Perceptions of Hope in Dyads of End of Life Patients and Their Caregivers in a Portuguese Palliative Care Unit: A Qualitative Study

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Background/aims: Hope plays a key role in providing comfort and quality of life for patients and families. In contrast, hopelessness is associated with anxiety, spiritual suffering, depression, suicidal ideation and physical illness. This study focused primarily on exploring how hope is experienced by dyads of EOL patients and their family carers and identifying factors that constrain or facilitate a dyad's shared perception of hope and how it is provided and received.

Methods: An exploratory qualitative study was performed using thematic analysis within a critical realist paradigm. Data were collected by in-depth interviews with seven Portuguese family dyads. All patients were in the EOL stage of an advanced oncological illness (as determined by the physician of the palliative care team; generally considered to be

the last months of life). Written informed consent was obtained from all participants before the interview. All procedures were aligned to COREQ (Consolidated Criteria for Reporting Qualitative Research) and SRQR (Standards for Reporting Qualitative Research) guidelines.

Results: The mean age of the patients and FCs was 49.9±10.6 years old (range 33-66) and 47.4±11.8 (range 37-65) respectively. All patients were diagnosed with advanced progressive cancer disease (stage 4); four of them suffered from metastatic gastrointestinal cancer. Family dyads noted several barriers and facilitators to perceptions of hope. Barriers to hope included limitations imposed by illness, feelings of helplessness, and poor communication with clinicians. Hope facilitators included supportive others, positive thinking and sense of humour, connection with nature, faith in religion and science, and a sense of compassion with others.

Conclusions: A holistic person-centred approach to support hope in family dyads experiencing advanced ill health is essential, which incorporates uncertainty and control as key drivers of the hope process.

Abstract ID: P03:57

Abstract type: Poster

Evaluating the Quality of End-Of-Life Care at a Private Hospital in Mexico City: A Retrospective Observational Study

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Background/aims: Timely cessation of chemotherapy and life-sustaining treatment is essential to avoid harm and provide quality care to patients with advanced cancer near death. To evaluate the quality of end-of-life (EOL) care in our Cancer Institute.

Methods: We performed a retrospective analysis of electronic medical charts of all patients with cancer who died at Centro Medico ABC Observatorio between January 2015 and February 2018. Quality of cancer care indicators were calculated for the use of chemotherapy during the last 14 days of life, and for emergency room (ER) visits, intensive care unit (ICU) admissions, prolonged hospitalizations (defined as longer than two weeks), cardiopulmonary resuscitation (CPR), and the use of invasive or non-invasive ventilation (NIV) within the last 30 days of life.

Results: A total of 243 patients were included in our study, of whom 58% were female and 42% were male, the average age was 63.13 years. The most common types of cancers were gastrointestinal, genitourinary, lung, and breast cancer. Sixty-seven patients (27.6%) received chemotherapy in the last 14 days of life, and 14.8% within the last 7 days. The ECOG performance status of these patients was 3 in 38.8% and 4 in 16.4%. During the last 30 days of life, 37 patients (14.5%) had two or more ER visits, 106 patients (43%) were admitted to the ICU, of whom 75 (30.9%) died there. Seventy-one patients (29.2%) had prolonged hospitalizations, 60 patients (24.7%) received invasive ventilation, 69 (28.4%) NIV, and 23 patients (9.5%) underwent CPR in the last 30 days of life.

Conclusions: According to proposed indicators of quality of cancer care, we are providing overly aggressive EOL care to patients with advanced cancer. Adopting an early palliative care approach could avoid unnecessary harm to patients and improve the quality of EOL care in our health care system.

Abstract ID: P03:58

Abstract type: Poster

Review of European Guidelines on Palliative Sedation: A Working Base for the Updating of the EAPC Framework

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Background/aims: Several guidelines on palliative sedation (PS) were developed in different geographical and cultural contexts with variations due to a lack of consensus on terminology and concepts.

Aim: As part of the Palliative Sedation project, we analysed guidelines on PS in eight European countries to inform the discussion on the planned revision of the European Association of Palliative Care (EAPC) Framework.

Methods: The three most used documents per country (n= 8) were identified through an online survey among 125 clinical experts in 12/2019. Those meeting guideline criteria were selected. Based on the work of Abarshi et al. (2017), their content was assessed against the EAPC Framework on PS and the quality of their development evaluated with the Appraisal Guideline Research and Evaluation II instrument.

Results: Nine guidelines were included for analysis. All recognized PS as a treatment of last resort for refractory symptoms but differed on how to determine the refractoriness of these symptom(s). Most of them recognised psychological or existential distress as (part of) an indication. All agreed that assessment should be multi-professional, but they diverged on the expertise required by the attending physician. Decisions on hydration and nutrition should be independent of those for PS, but there is no clear consensus on the decision-making process. Weaknesses are highlighted particularly in the areas of rigour of development and applicability.

Conclusions: The highlighted points of debate will inform the discussion on the planned revision of the EAPC framework on PS. For any updating or revision of the analysed guidelines, the identified methodological weaknesses should be considered to improve the quality of their content and the applicability of their recommendations.

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Abstract ID: P03:59

Abstract type: Poster

The Influence of Homecare-Specific Circumstances in Specialist Palliative Homecare on Sedation

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Background/aims: Existing data on sedation at the end of life indicate difficulties with the implementation of guideline recommendations in the homecare setting, leading to deviations from guidelines or non-provision of sedation at home. We aimed to explore homecare-specific circumstances in specialist palliative homecare, which influence the practice of sedation.

Methods: 59 semi-structured qualitative interviews and two focus groups with physicians, nurses, and other members of the multiprofessional team. Recruitment took place via contact persons in 10 palliative care units and 7 home care teams. We thematically analysed the transcripts with the Framework approach, using MAXQDA version 2018.2.

Results: Participants reported homecare-specific circumstances that can be categorized into three interrelated topics: (1) Lack of round-the-clock on-site availability, (2) active involvement of the family, and (3) challenges regarding teamwork and multidisciplinary. Participants drew very different conclusions from the reported homecare-specific circumstances regarding the feasibility of different types of sedation at home: While some reported to generally use all types of sedation, others stated that some types of sedation are not feasible in homecare, e.g., deep sedation until death. Most participants questioned the applicability of existing sedation guidelines in the home care setting.

Conclusions: Our data indicate that sedation practices might currently follow the healthcare professional's attitude or service policy rather than the patient's need. To avoid hospital admission in manageable cases and ensure that homecare-specific best practice standards are met, existing guideline recommendations have to be adapted and supplemented by additional supporting measures specific for the homecare setting.

Abstract ID: P03:60

Abstract type: Poster

Variations in Clinical Practices in Dutch Hospice Care

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Background/aims: Inpatient palliative care is provided by three types of hospices in the Netherlands – Volunteer-Driven Hospices (VDH), Stand-Alone Hospices (SA), and Hospice Unit Nursing Home (HU) - with considerable variability regarding their organisation, care processes, care providers and patients. It is not known how clinical practices may vary between hospice types. National clinical guidelines have been developed in the Netherlands to reduce variations of care processes and improve quality of care.

This study aims to examine clinical practices in palliative care through different hospice types, to identify variations in care.

Methods: Retrospective cross-sectional cohort study utilising clinical documentation review. Cross-sectional cohort of 803 patients receiving inpatient palliative care at 48 different hospices who died in 2017 or 2018. One quarter of patient were randomly selected for in-depth clinical review or if they have received palliative sedation therapy. Care provision for each patient for the clinical practices of treatment for pain, delirium and palliative sedation were analysed according to the Dutch national guidelines.

Results: 112 patients were included who received treatment for pain, 53 for delirium, and 116 patients who underwent palliative sedation

therapy. Care was provided in accordance with guidelines for delirium in 29%, 78% and 79%, pain in 32%, 61% and 47%, and palliative sedation in 35%, 63% and 42% of patients who received care in VDHs, SA, and HU respectively. For all clinical practices, patient care was conducted according to the guidelines for 32.6% of in VDHs, 64.8% in SAs, and 49.5% in HUs.

Conclusions: The data demonstrates that care practices are not standardised throughout Dutch hospices and exhibit substantial variations between types of hospice.

Abstract ID: P03:61

Abstract type: Poster

Determinants of Suicidal History Prior Assisted Versus Self-Initiated Suicide Late in Life

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Background/aims: Older adults make up a growing proportion of the world's population and are exposed to a range of risk factors which can increase vulnerability to suicide. The link between prior suicide attempts and assisted suicide in the elderly has not been investigated to date. Data related to potential previous attempts before assisted suicide, the temporality between suicide attempts and completed assisted suicide and the determinants of such a suicidal behavior remain scarce.

Methods: We compared all recorded suicide cases aged 65 and above in a retrospective study spanning 10 years (2010-2019) in our region, using forensic and hospital records.

We hypothesized that there is an overlap between assisted and self-initiated suicide determinants, and that the risk factors recognized for self-initiated suicide, such as prior hospital-treated attempts, mental disorders, life stressors are also present in older populations who died by assisted suicide.

Results: Over the past 10 years, assisted suicide mortality rose among elderly people and self-initiated suicides rates declined. The number of older people who have attempted suicide before engaging in assisted suicide has exceeded the total number of self-initiated suicide cases.

In the 2 groups, individuals had most often made only 1 attempt, sometimes more than 10 years before the fatal act, mostly by medication poisoning, having led to admission to the emergency room and hospitalization in psychiatry. The shortest span between the last attempt and death was less than 1 month in both groups. The risk factors for suicide frequently found in the 2 groups were depressive and anxious disorders, addictions, abuse and abandonment during childhood, bereavement after a violent death.

Conclusions: The complex links between assisted suicide and other forms of suicidality are arguments for recommending the development of a suicide prevention strategy applicable to both types of suicide cases in the elderly population.

Abstract ID: P03:62

Abstract type: Poster

What Does "Assisted Dying" Mean for Professionals Providing End-Of-Life Care? Results From a Nationwide Qualitative Study

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Background/aims: Assisted Dying (AD) remains a highly controversial and vivid debate, raising ethico-clinical and conceptual challenges. The etymology of AD can give various meanings and interpretations, which may or may not be aligned with the intrinsic ethical values and principles of palliative care (PC).

Aim: To explore the concept of AD among professionals providing end-of-life care (EOLC) and understand differences and ethical implications.

Methods: Qualitative study.

Instrument: In-depth interviews.

Participants: Professionals working in PC and intensive care (IC) in Portugal.

Sampling procedure: Purposive and snowball sampling until theoretical saturation.

Data collection: From June 2016 to March 2020.

Analysis: Inductive thematic analysis.

Results: 58 professionals interviewed. Eight themes emerged: (i) AD as synonym of dying with dignity; (ii) AD as accompanying someone in the process of dying; (iii) AD as comfort care at the EOL; (iv) AD as "intensive PC" (i.e., active and specialist PC) at the EOL; (v) AD as an euphemism for intentionally hastening death (HD); (vi) AD as an ambiguous concept (i.e., "it can mean anything"); (vii) AD as synonym for euthanasia and assisted suicide; and (viii) Distinction between the etymological definition of AD and the societal and mass media ones. While almost all professionals in PC made a clear distinction between AD and HD, professionals in IC tended to consider AD as an ambiguous term. Out of 26 professionals in PC, only 2 physicians defined AD as a synonym for HD and were willing to do it, even if it is recognised by the EAPC as an act that should not be included into the practice of PC.

Conclusions: Several meanings are given to AD. Most meanings given by professionals in PC are aligned with the core ethical principles and values of PC. The etymological meaning of "assisted" is not to hasten, but rather to give support or help, to make it easier for someone or for something to happen. Societal and mass media meanings increase haziness and ethico-clinical debates.

Other Disciplines, Methods and Care Organisation

Abstract ID: P04:01

Abstract type: Poster

Driver and Facilitator for Public engagement in Palliative Care

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Background: Integral model of PC recognizes community as essential element in improving patient/families's QoL, it is necessary to find formula allows community to have voice in design and implementation of PC policies and initiatives.

Aim: describe drivers and barriers for community involvement in PC.

Methods: Scoping review: NICE, Cochrane Library, Health Evidence, CINAHL and PubMed. Keywords: Palliative care/End of life care/community networks, engagement, involvement, participation/social participation/barrier-facilitators. Between 2016- 2021. Empirical studies, systematic reviews.

Results: 729 results, 45 reviewed, 11 selected. 4 categories: Public health/community involvement; community attitudes towards PC,

death/preferences at the EoL; importance of volunteers in community; compassionate communities.

Barriers: Resistance asking or accepting help; Misperceptions, knowledge gaps; Weakness in conversational skills. Volunteer role; Fragmented care model; Non integration health care systems/social welfare system; No PC Public health approach; Resistance thinking about death/Social taboo/Stress and fear; minorities differences; Fear of upsetting others; **Beliefs:** others are unwilling to have conversations; Confusing Online information.

Drivers: Impulsion Compassionate Communities; Shared Care Model of PC/social welfare/Public Health Approach; Training on EOL conversations; emotional and social support; Acceptance of Death as natural/ Addressing fear; Raising awareness of relevance people; surrounding death; Engolve Hospice and schools together; Training: knowledge/communication skills/targeted, accurate and consistent messages.

Conclusions: Community capacity includes normalizing death and preparing communities for EoL. Sensitizing/involving society to know what society is and can offer, identifying/bringing values, resources and experience. The community is compassionate, but needs to channel potential.

Abstract ID: P04:02

Abstract type: Poster

‘Legislate on Palliative Sedation? I Am Not Really in Favour’ an Exploratory Multicentre Study With Swiss Palliative Care Physicians

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Background/aims: Many international studies show that the opinions, decisions and practices of continuous deep sedation until death (CDSUD) are heterogeneous across the world. In culturally pluralistic countries, there are variations between linguistic regions, and some linguistic regions may share cultural characteristics with the neighbouring country. In Switzerland, CDSUD is not legally regulated. In contrast, France is the first and only country in the world to regulate this practice explicitly at the legal level. This suggests that issues related to CDSUD in the French-speaking part of Switzerland may be influenced by the law and discourse in France.

Our study aimed to explore the opinions of palliative care physicians working in the French-speaking part of Switzerland on potential legal regulation of CDSUD, and to assess if any such legislation on CDSUD should be similar to that in France.

Methods: A multicentre exploratory qualitative study based on interviews with 12 physicians working or who have worked in palliative care units in the French-speaking part of Switzerland. Inductive thematic analysis conducted of all transcripts.

Results: Most of the participants were opposed to legal regulation of CDSUD in Switzerland. Their arguments were manifold: they were focused on general and/or medical and/or epistemological aspects of CDSUD or were presented from a legal perspective. Many of the participants based their argument on the risks legal regulation could pose for their practice. Two participants hesitated and presented arguments both against and for legal regulation. One participant fully agreed with regulating CDSUD at the legal level. No participant was familiar with the French law on this practice.

Conclusions: Our study adds several new pieces of information to the discussion of the legal and ethical challenges of CDSUD and,

consequently, how current debates on this practice should be approached and addressed. All efforts should be made to offer open societal discussion.

Abstract ID: P04:03

Abstract type: Poster

Dying With Dignity: Conceptual and Practical Similarities and Differences Among Professionals Providing End-Of-Life Care

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Background/aims: Dignity is a key feature and ethical principle of providing care for patients who are dying. Yet, evidence shows that dignity is anchored and poorly defined. Clinical practices differ on how to promote dignity in real world life.

Aim: To explore the concept of dying with dignity and its practical implications.

Methods: Qualitative study using in-depth interviews with professionals providing end-of-life care in different settings (palliative care, home care, medical and geriatric services, long-term care, intensive care, burn intensive care). A combination of purposive and snowball sampling was applied until reaching theoretical saturation. 53 professionals (e.g., physicians, nurses, psychologists, social workers) working in the Portuguese healthcare system (public and private; rural and urban; nationwide, including Azores and Madeira) participated. Data collected from June 2016 to October 2020. A thematic content analysis was done to transcripts of interviews.

Results: Five themes emerged and were divided in sub-themes: (i) Respect for autonomy (respecting persons' choices and wishes; respecting persons' beliefs; managing expectations); (ii) Person-centred (very individual subjective concept); (iii) Respect for integrity (existential integrity; keeping a sense of being; meaning); (iv) Respect for beneficence/non-maleficence (symptom control; comfort and safety; without patient, family and healthcare professionals' suffering); and (v) In peace. Differences were found mainly among professionals working in intensive care who emphasised that dying with dignity meant (i) dying without medical futility or (ii) "simply dying". Professionals distinguished between dying with dignity for them and for the patients they cared for.

Conclusions: Dying with dignity is highly personal and subjective, posing ethical challenges in daily clinical practice. Respecting ethical principles and values is paramount to ensure that patients die with dignity and minimum suffering for them, their families, and carers.

Abstract ID: P04:05

Abstract type: Poster

Educating the Public about Research on Advance Care Planning in Later Life: Lessons from the People's Research Café

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Background/aims: Advance care planning (ACP) research in older age with its impact on patients, carers, clinicians and wider society, should be communicated to the public beyond the remit of academic journals. The low uptake of ACP in later life highlights the need to educate the public on this crucial topic. Therefore, this study aimed to establish how to communicate to the public findings from ACP research in later life including:

- 1) where to communicate research findings to maximise societal impact
- 2) what format to communicate research
- 3) how to reach a diverse audience.

Methods: A People's Research Cafe was conducted at an outdoor university showcase event communicating medical research, co-hosted by an academic doctor and a lay older carer. This provided a relaxed outdoor cafe environment to have meaningful conversations about how best to convey ACP research in older age to the general public. The public was invited to hear about ACP research and asked about how to communicate ACP research across society. Ideas from the visiting public were written on flash cards and collected by the co-hosts.

Results: The public highlighted the importance of a trans-generational approach when communicating research about ACP in later life, including younger members of the public who may be carers or affected family members of older persons. A multi-pronged approach was proposed to maximise societal impact involving online media and written communications. This included communications targeting older adults and general healthcare settings, particularly primary care, the voluntary sector, patient and carer advocacy groups, and working with diverse groups of local community leaders. Repeated, consistent and clear messages were recommended.

Conclusions: ACP research is welcomed by the public. Research findings should be communicated in a way that is accessible, clear and relevant. A multi-pronged, trans-generational approach is deemed most likely to maximise impact and engage diverse groups.

Abstract ID: P04:06

Abstract type: Poster

Learning Together: A Training Needs Analysis to Promote Inclusion of Hospice Staff in the Development of an Educational Strategy

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Background: In order for healthcare professionals to feel confident in their role it is important that their educational needs are met. A training needs analysis is essential in establishing the continuing professional development of a health care workforce.¹ Training needs analysis looks to identify gaps in knowledge and skill for an individual or organisation, allowing the trainer and the person/s requesting training to develop an educational plan together².

Aims: To improve confidence amongst staff by identifying gaps in knowledge and forming an educational plan to meet their needs.

Methods: An online and paper based questionnaire was developed, giving hospice staff the opportunity to be involved in developing their own plan of education. Consisting of 35 questions, the survey asked individuals to self-assess different aspects of their own work. For each topic respondents were asked to rate how important they felt the topic was to their role and how confident they felt in this area. A final question provided the opportunity for respondents to give free text responses on their hopes and requirements for future education.

Results: We received 38 responses from different healthcare professionals working in the hospice. Results of the questionnaire identified gaps in knowledge amongst different disciplines, providing us with the essential information needed to develop an educational strategy to meet the needs

of our staff. Feedback from staff has been positive as they have reported a feeling of inclusion and an appreciation of having their voices heard.

Conclusions: Developing a training needs analysis to identify the educational needs of hospice staff has proven to be successful, positively engaging staff in order to develop an inclusive plan of education.

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Abstract ID: P04:07

Abstract type: Poster

An Inter-Professional Training Program for Mediators and Palliative Care Hospital Professionals; A Pilot Study and Its Evaluation

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Background/aims: Oncological patients with migrant background represent a vulnerable population with high risk of lower quality care. Many difficulties have already been described during mediation. Better interactions with these patients is a challenging competence for a Specialized Palliative Care service (SPCS).

The primary aim of the study 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" (TBL) methodology"
- role-play
- clinical practice in medical consultations (MC).

Participants were 8 mediators from 4 different ethnic groups, 3 doctors and 3 nurses of a SPCS. The evaluation was made by the triangulation of data coming from portfolios, qualitative interviews, and participants' field notes during MC.

Results: The training program was established as planned from May to September 2021.

The evaluation will be realized at the end of MC.

Preliminary data suggest that mediators better understood the MC' objectives in delivering bad news and some palliative care specificity. They also recognized emotional support by SPCS. Health professionals, on the other hand, reported a lower impact of role play on their habitual practice, while they evaluated the part of TBL methodology as interesting and useful. All the participants recognized the value of mutual training and sharing.

Conclusions: We piloted a new training program that could improve collaboration between mediators and SPCS and, consequently, impact on care of migrant background patients.

Abstract ID: P04:08

Abstract type: Poster

Evaluation of Training Needs in Palliative Care for Young French Oncologists (PALLIA TRAINING 1 Study)

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Background/aims: Radiation and oncology residents are regularly confronted with palliative situations. However, in France, they have little training in Palliative Care (PC) regarding their teaching program and their traineeship model. The main objective of this study was to explore from the radiation and oncology residents perspectives their needs regarding their training in PC.

Methods: A national descriptive qualitative study was conducted from November 2020 to June 2021. A semi-structured interview guide was developed after a review of literature. To have the most representative vision of national disparities, the respondents, after a call for volunteers, were selected according to their year of training and their region of practice. Interviews were taped-recorded and transcribed. Each member of the research team analyzed each interview separately according to the themes and afterward results were compared and any discrepancies discussed and resolved.

Results: Data saturation was obtained after 8 interviews including participants from 4 French regions. Three of them completed a 6-month training in a PC Unit. Concerning needs, communication and family meetings management were plebiscited. Symptoms management was a secondary need. About solutions, having a medical training in a PC unit was highlighted. However, access to a PC Unit training seemed to an issue due to oncology pedagogical teachers. The lack of palliative culture was illustrated by a narrow view of PC definition reduced to the end of life and by a non-integrated and non-collaborative vision between oncology and PC. Visibility and quantity of PC teaching during medical study seem to be the source of this lack of PC knowledge.

Conclusions: The implementation of palliative culture seemed to be still insufficient in oncology in France. Including a PC unit medical training during oncological traineeship seemed to be a solution. A national quantitative study is therefore needed and about to start.

Abstract ID: P04:09

Abstract type: Poster

The Efficacy of Training Programs for a Palliative Care Approach: A Systematic Review of Intervention Trials for Health Care Professionals
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Background/aims: Palliative care (PC) training initiatives have proliferated to assist health care providers (HCPs) develop skills for applying a PC approach. There has been little synthesis of high-level evidence to review the content and efficacy of these programs. To address this gap in knowledge, we conducted a systematic review of trials of training interventions to build PC competency in HCPs, according to PRISMA guidelines.

Methods: We searched MEDLINE, CINAHL, PsycINFO, Embase, HealthSTAR, etc., for studies published since 2000. Eligible studies were trials assessing PC training for HCPs. Interventions had to address at least two of six PC-related domains, based the National Consensus Project: Identification or Assessment; Illness understanding; Symptom management; Decision making (e.g., ACP); Coping (patient and caregivers); and Referral (coordination/care planning). Two reviewers independently assessed articles for inclusion (Rayyan collaborative review platform) and extracted relevant data.

Results: Of 1209 articles reviewed, 21 studies met the inclusion criteria, with the majority conducted in Europe (n=8) or USA (n=8). 18 of the studies collected data through self-reported surveys; administrative

(n=4), clinical outcomes (n=3), or interaction analysis (n=5) data were also or solely used. Interventions featured didactic, skill-based training followed by role play and/or individual coaching. Few involved comprehensive PC training, with 11 studies representing 3 or less of the 6 framework domains. Most (n=16) reported a significant positive impact on at least one outcome, most often on HCP self-reported outcomes.

Conclusions: Most of the interventions taught only a few of the 6 PC-related domains in the framework. While many of these interventions improved confidence among HCPs in the domains taught, findings were mixed on more objective outcome measures. Further trial-based evidence is required on comprehensive PC training to help inform these interventions for HCPs.

Abstract ID: P04:10

Abstract type: Poster

Family Meeting: A Scoping Review on Training for Healthcare Professionals

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Background/aims: Effective communication between patient, families and healthcare providers is integral to optimal palliative care (PC). Family meeting (FM) is recognized as one of most efficient interaction to share informations between staffs and families. Although FM are often used, the literature shows a lack of training to conduct them or even participate to.

Aim: To provide an overview on FM education for healthcare professionals (HPs).

Methods: Based on PRISMA-ScR, we conducted a scoping review of empirical studies, searching MEDLINE, Embase, Cinahl, Psycinfo, and Scopus, from inception to September 2021. The mesh terms were: (Family meeting OR Family conference)AND(education*OR learning OR training OR course*ORworkshop*OR teaching OR seminar*OR classe*OR instruction). The search was conducted based on the definition of FM as “meetings between the patient, their family and HPs are undertaken for multiple purposes including the sharing of information and concerns, clarifying the goals of care, discussing diagnosis, treatment, prognosis and developing a plan of care for the patient and family carers”. The screening for title and abstract of retrieved studies and full text assessment has been carried out by three reviewers. We are analyzing self-assessment of skills acquisition, FM Communication Assessment Tool in all setting of care, methods and strategies in educational programmes.

Results: 572 title and abstract analysed. The final data will be presented at the Congress.

Conclusions: The results of this review may provide elements for PC professionals to improve education programs addressed to HPs for their specific competences in conducting FM.

Funding: This research was funded by the Italian Ministry of Health as part of the program “5 per Mille, year 2019” promoted by the AUSL-IRCCS of Reggio Emilia.

Abstract ID: P04:11

Abstract type: Poster

Self-Assessment of Basic Research Competencies for Palliative Care Clinicians - Pilot Testing

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Background/aims: RESPACC is an Erasmus + funded project aimed at developing framework with basic research competencies for palliative care clinicians (PCC) and adjacent education materials (<http://www.stu-diipalliative.ro/projects/research-respacc/>). The Framework was developed together with a self assessment quiz to guide PCC on areas of research that need further development

Methods: The self assessment quiz included questions for each of competencies in the 7 domains of the framework, based on examples provided for each competency in the framework. A 5 point scale with following categories Novice, Advanced beginner, Competent, Proficient, Expert (each clearly defined) was used by PCC to self asses their competencies. The quiz was translated in national languages of partners and Survey monkey was used to administer the quiz. For piloting purpose the quiz was tested out on Romanian PCC attending the the National Palliative Care Conference. Questions about demographic data, clarity of the quiz and suggestions for improvements were asked. After scoring each domain feedback was automatically provided.

Results: 25 PCC (19 women, 6 men) participated in the pilot testing (Physicians 18, nurses 4, Psychologist 2, Physiotherapist 1); Most (15) had less than one year experience in palliative. The results per domains are in the table below:

Domain	Novice	Advanced beginner	Competent	Proficient	Expert
1. The clinical context	10	5	6	3	1
2. Scientific thinking and research design	6	10	5	3	1
3. Ethics and regulatory framework for research	8	7	5	3	2
4. Study and site management	9	5	4	5	2
5. Data management and informatics	10	5	4	3	3
6. Communications and relationships	9	7	3	3	3
7. Research leadership	7	4	4	5	5

All PCC considered the quiz clear. They enjoyed receiving immediate feedback on each domains assessed framed in a positive language

Conclusions: The self assessment quiz is reliable, useful and easy to use for PC clinicians to asses their competencies and education needs concerning research

Abstract ID: P04:12

Abstract type: Poster

A Palliative Care Approach for Adult Non-Cancer Patients with Life-limiting Illness Could Be Resource Saving: A Systematic Review

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Background/aims: A palliative care approach has been shown to reduce healthcare resource use at the end of life in patients with a cancer diagnosis. The evidence is inconclusive for patients with non-cancer diagnoses.

Aims: To determine the difference in resource use between a palliative care approach and usual care in adult non-cancer patients with a life-limiting illness.

Methods: A systematic review using a narrative synthesis approach. We searched Medline, CINAHL, EconLit, EMBASE, TRIP, NHS Evidence, Cochrane Library and Web of Science. Inclusion criteria were

- (1) any empirical research;
- (2) adult patients with non-cancer life-limiting illnesses;
- (3) a palliative care approach as defined by the WHO and
- (4) a comparator group of standard or usual care.

Study quality was assessed with a modified version of the Drummond checklist.

Results: 26 retrospective studies and seven prospective studies were included. The retrospective studies examined a range of diagnoses and outcome measures and reported a total of 103 comparisons.

The prospective studies suggested that a palliative care approach is resource-saving. Results from the retrospective studies depended on the type of outcome measure. Most comparisons for physical outcome measures such as hospital admissions or length of stay suggested a palliative care approach is resource-saving. For monetary outcome measures, less than half of the comparisons suggested a palliative care approach is resource-saving. The funding model for palliative care affected the results for monetary outcome measures, with hospital palliative care being resource-saving and Medicare hospice care mostly being resource-use increasing.

Conclusions: Palliative care is resource-saving to healthcare systems, especially when resource use is measured in physical units (such as time in hospital), which are less likely to be influenced by the funding model. These findings lend support to calls to increase palliative care provision globally.

Abstract ID: P04:13

Abstract type: Poster

Economic Analysis of a Decision Aid for Family Carers of People With Dementia: A Feasibility Study

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Background/aims: There are currently around 700,000 family members and friends acting as primary carers of people with dementia in the UK. Family carers find decisions about severe dementia and end of life difficult and therefore they may benefit from support in making decisions. For this study we developed a decision aid to support family carers making decisions on behalf of the person with severe dementia. The overall aim for our study was to test the acceptability of a decision aid for family carers. Here, we focus on the aim to assess the feasibility of collecting health economic and resource utilisation data.

Methods: Feasibility study using a before-after design with family carers of people with severe dementia. We collected data on quality of life (EQ-5D-5L) and resource utilisation data (RUD-Lite). We calculated the quality adjusted life years for family carers and estimated the value of costs associated with implementing the decision aid.

Results: 26 family carers completed the baseline measures. 20 (77%) of the family carers were followed up at 6 months. There were no missing items on either the EQ-5D or the RUD-Lite for the participants that were followed-up. There was no change in quality of life across the 6 months (Baseline mean (standard deviation) = 0.9 (0.1), 6 month follow up mean (SD) = 0.9 (0.2); Mean difference = -0.0, 95% CI (-0.09, 0.01)). 75% of the family carers were the main care givers, providing at least 60% of the care

for the person with dementia. Most family carers (60%) saw a health care professional in the 3 months prior to the final follow-up.

Conclusions: Family carers were able and willing to take part in the study and did not object to questions about quality of life and resource use. We need further evidence to say if the decision aid intervention is cost effective compared to usual care. The findings from this study may be used to determine the design of phase III randomised controlled trial.

Abstract ID: P04:14

Abstract type: Poster

Perceptions and Knowledge of End-Of-Life Medical Situations Among Older Adults in Switzerland

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Background/aims: Perceptions and knowledge regarding health care situations at the end of life can influence individuals' advance care planning, such as the completion and content of advance directives. We aimed to assess the perceptions and degree of accuracy of medical end-of-life situations in a nationally representative sample of adults aged 58 years and older in Switzerland.

Methods: Our data originate from a paper-and-pencil self-administered questionnaire survey incorporated into wave 8 (2019/2020) of the Swiss part of the Survey of Health, Ageing, and Retirement in Europe (SHARE). Respondents evaluated the likelihood of 11 end-of-life situations on a four-point scale (1= very unlikely (0-25%), 2= rather unlikely (26-50%), 3= rather likely (51-75%), 4= very likely (76-100%)).

Results: The results were quite heterogeneous and showed high percentages of inaccuracy regarding the place of death in Switzerland (>72%), overestimation of the prevalence of dementia (>78%) as well as a rather low level of accuracy regarding pain management effectiveness (<38%) and artificial nutrition and hydration utility in a situation of imminent death (<35%). Most respondents had unrealistic expectations of the survival rate after cardiopulmonary resuscitation at older ages (>92%). Inaccurate views on the eleven end-of-life medical situations were more frequent among men than women ($p < 0.01$) and individuals with financial difficulties compared to those without ($p < 0.05$). Adults aged >75 years ($p < 0.01$) and those from the German-speaking part of Switzerland ($p < 0.01$) appeared to have more accurate perceptions of healthcare-related end-of-life realities in Switzerland.

Conclusions: Our findings suggest that interindividual differences in perceptions of end-of-life medical situations may be an important factor explaining variations in advance care planning behavior. The generally low degree of accuracy suggests considerable scope for end-of-life health literacy-enhancing interventions.

Abstract ID: P04:15

Abstract type: Poster

Researching Compassionate Communities From an Interdisciplinary Perspective: Development of a Research Framework

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Background/aims: Compassionate Communities (CCs) are places in which people collaborate and leverage local resources, networks and institutions

to improve the circumstances, health and wellbeing of those facing serious illness, death, dying and loss. Studying their development, implementation and evaluation requires interdisciplinary research approaches, currently lacking. This paper aims to present CCs as an interdisciplinary field of study and propose a corresponding research approach.

Methods: In 2020, 8 research groups from 4 faculties – including health sciences, sociology, psychology, educational sciences and geography – formed the Compassionate Communities Centre of Expertise (COCO) at the VUB University in Brussels, Belgium. Interdisciplinary exchange spaces were created via bilateral and group discussions, and collaborative seminars to develop a shared conceptual understanding of CCs within a collaborative research framework.

Results: We developed minimal definitions for 'compassion', 'community' and 'compassionate communities' to provide common ground for all perspectives present in COCO. The research framework emphasizes co-creation and includes partnering with Living Labs. At present, three Living Labs have been developed: the Compassionate City of Bruges, the Compassionate City of Herzele, and the Compassionate University (VUB). The resulting research agenda encompasses 3 themes: 1) operationalizing & measuring compassion; 2) CC transitions and sustainability; and 3) CC-building in different community types.

Conclusions: This project succeeded in establishing bridges between university faculties and disciplines, and an interdisciplinary research framework for the study of Compassionate Communities was developed. COCO is funded by the Vrije Universiteit Brussel (VUB) as part of its Interdisciplinary Research Program (IRP16) framework.

Abstract ID: P04:16

Abstract type: Poster

Rapid-PCST: Screening for Palliative Care Needs in Emergency Calls at a Metropolitan Ambulance Dispatch Center

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Background/aims: Emergency Medical Services (EMS) are often called to end-of-life patients. However, it is challenging to identify patients with palliative care needs. Project TIERA (Terminal Illness Early Recognition in Ambulance Settings) is focused on early recognition of terminal patients within the EMS in Prague, Czech Republic. Its aim is development and pilot evaluation of Rapid-PCST, a novel screening tool to identify patients with palliative care needs in EMS settings.

Methods: Rapid-PCST was derived from the validated Palliative Care Screening Tool (PCST) and uses three selected items that an EMS practitioner is able to evaluate while responding to the emergency call. All calls to the Prague EMS are screened for Rapid-PCST criteria since July 2021.

Rapid-PCST triage criteria:

Cancer (Metastatic/Recurrent) or advanced COPD or end stage renal disease or advanced cardiac disease or advanced neurodegenerative disease; AND recent multiple unplanned visits to emergency department; AND recent deterioration in functional status or unacceptable level of symptom distress.

If all three criteria are met, the call is classified as "palliative relevant patient". Their further trajectory within the healthcare system is tracked and clinical status documented. Sensitivity and specificity of Rapid-PCST is evaluated on 250 identified calls. Quantitative data are supported by semi-structured interviews focused on exploring the caller's perspective.

Results: Preliminary results (07-09/2021, n=129 patients) indicate high relevance of Rapid-PCST in cancer patients.

Non-cancer patients are under-represented.

Conclusions: Rapid-PCST seems to be a feasible tool to indicate palliative care needs in emergency calls. Non-cancer patients are under-represented;

this could be caused by Rapid-PCST flaws or cultural patterns in clinical practice in EMS settings. Integrating palliative care within EMS can prompt access to palliative services and limit the use of intensive care. Complex analysis will be available by the end of 2021.

Abstract ID: P04:17

Abstract type: Poster

Ba'ad al-sharr: Cultural Barriers to Community-Based Hospice Care in Egypt

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Background/aims: Home-based hospice care in Egypt remains scarce and clustered in the urban center of Cairo, with an estimated 1:25,000 ratio of hospice providers per capita in need of services. Hospice Egypt, an Egyptian non-governmental organization (NGO), has sought to broaden access to hospice through direct service and advocacy. While hospice organizations globally face common challenges, few studies have devoted attention to the specific barriers to hospice development in Egypt. The aim of this study was to explore the perceived cultural barriers Hospice Egypt faces in expanding their services and promoting awareness about palliative and hospice care.

Methods: Between July-August 2019, qualitative interviews were conducted with physicians, pharmacists, volunteers, and patients of Hospice Egypt to ascertain these stakeholders' perceptions of the barriers to cultural acceptance of hospice care. These interviews were then reviewed, coded, and compared with observational data regarding in-home service provision and organizational management to determine barriers affecting awareness and promotion of hospice services in Egypt.

Results: Four barriers to hospice development in Egypt were identified through thematic analysis: 1) cultural taboos around discussing death and dying; 2) perceived religious perspectives on end-of-life medical management; 3) lack of a suitable translation for "hospice" in Egyptian Arabic; 4) fundraising challenges facing NGOs in post-Revolution Egypt.

Conclusions: Hospice organizations in Egypt face unique, region-specific barriers to creating awareness and infrastructure for home-based hospice care. These findings have implications for enhancing local hospice advocacy and development efforts, particularly in the setting of resource constraints. Addressing these barriers could not only help streamline Hospice Egypt's work but also aid international palliative care and hospice partner organizations in better supporting local development efforts.

Abstract ID: P04:18

Abstract type: Poster

Comparison of Symptom Burden Between Patients of in Palliative Care Units of Oncological Centers of Excellence and Other Hospitals

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Background/aims: The National Hospice and Palliative Registry (NHPR) is a database for palliative care facilities to voluntarily document a core data set. These data are used for quality assurance, scientific evaluations and benchmarking. The study aims to capture differences in symptom burden between patients in palliative care units treated in oncological centers of excellence (CCCs) and other hospitals (OHs).

Methods: Based on anonymized data from day of admission and discharge/death of patients treated in palliative care units and registered in the NHPR from 2014 to 2018 18 symptoms were analysed descriptively. Group comparisons were performed using IBM SPSS Statistics 21.

Results: In total, data from 12,922 patients were included (CCC n=4,975 / OHs =7,947). For CCCs and OHs, the symptom "weakness" ranked first with the highest number of patients with moderate or severe symptom burden both at admission and at discharge followed by the daily / strong / high "need for assistance with activities of daily living". Group comparisons showed a significant difference between CCCs and OHs for 12 of the 18 symptoms at admission (significant higher symptom burden at OHs at 10 symptoms) and for 16 of the 18 symptoms at discharge. At discharge, OHs had significantly higher mean symptom burden for the eight symptoms vomiting, nausea, depression, pain, shortness of breath, anxiety, tension, and constipation compared with CCCs.

Conclusions: Data from the NHPR reveal differences in symptom burden at admission and discharge between patients in palliative care units with different Intensity of symptoms in CCCs and OHs. The differences could be due to other factors, like distribution of main diagnoses or ECOG status, needing further research. More detailed knowledge of differences in symptom burden among patients in CCCs and OHs may be helpful to improve therapies for symptom burden relief as well as palliative care structures for oncology patients in CCCs and OHs.

Abstract ID: P04:19

Abstract type: Poster

Public Knowledge and Attitudes Towards Advance Care Directives on a Sample of Portuguese Adults: A Cross-Sectional Online Survey

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Background/aims: Few studies have been conducted on public perspectives regarding EOL issues, including attitudes towards Advance Care Directives (ACDs). Better public awareness and openness to discuss death and EOL issues is needed to improve ACDs completion. This study aimed to ascertain the knowledge, attitudes and preferences of a sample of Portuguese adults regarding EOL care and ACDs.

Methods: An online cross-sectional survey using a convenience sampling method was conducted. Portuguese participants accessed the link to the online questionnaire through various social media platforms and emails. The survey instrument included three sections: information on sociodemographic factors, knowledge, attitudes and preferences regarding advanced decisions and EOL care. Participants were informed that the survey was anonymous and voluntary and that they could withdraw their participation at any time.

Results: In total, 1024 participants completed the survey with a response rate of 64%. Ages ranged from 18 to 78 years (mean=40.88; SD=11.41), corresponding to an adult population of working age. Despite 76.37% of participants having heard of ACDs, only 2.34% has ever completed one. Nearly all participants (98.71%) correctly indicated a distinction between ACDs and euthanasia. There was a high percentage of incorrect answers to the question related to organ donation and ACDs (61.31%), revealing a lack of discrimination between both topics. There was some ignorance regarding the Health Care Prosecutor (HCP), with 42.46% considering that their appointment is mandatory whenever an ACD is made, and 94.61% indicating they did not know the function of the HCP. Lastly, the results also suggest a positive attitude towards ACDs.

Conclusions: Educational materials or media campaigns might be helpful to encourage EOL discussions. Thus, health care professionals should attempt to increase public knowledge of ACDs by providing a comprehensive explanation of EOL decisions and ACDs.

Abstract ID: P04:20**Abstract type: Poster****Opioid Disposal Practices of Patients with Life-Limiting Cancers in an Outpatient Palliative Care Clinic***J. Lau*¹¹Princess Margaret Cancer Centre, Supportive Care, Toronto, Canada

Background/aims: Opioids are among the most common medications that are wasted by patients. The large quantities of opioids provided to patients receiving palliative care can accumulate in the last years of life. Proper prescription opioid disposal is essential to prevent poisonings and deaths. This study examined the opioid disposal practices in the outpatient palliative care clinic in Canada's largest centre for cancer care and research, Princess Margaret Cancer Centre.

Methods: This cross-sectional study involved a retrospective chart review of new, adult patients who were seen in the Princess Margaret Cancer Centre outpatient palliative care clinic between September 2018 and August 2019 and completed a survey about opioid use. This survey contained 25 questions that included screening questions for opioid use disorder and questions about the following opioid-related constructs: source of prescriptions, use, storage, disposal and knowledge about associated harms.

Results: This study included a total of 122 patients, and 52% (58/111) reported that they did not routinely dispose of their opioids. The most common method of disposal reported by 79% of patients was returning unused opioids to pharmacists. Cannabis and neuropathic medication use (OR 3.0, 95% CI 1.2 – 7.2) were positively associated with routine disposal of opioids. Patients who reported receiving pharmacist or physician education about opioid disposal were more likely to be aware of proper disposal methods (100% vs 54%, $p < 0.001$), dispose of opioids by giving them to pharmacists (72% vs 38%, $p < 0.001$), conduct pill counts (57% vs 29%, $p = 0.002$) and have knowledge about drug-take back programs (45% vs 17%, $p = 0.002$). Whereas, patients were less likely to routinely dispose of their opioid if they responded "Yes" to "Have you had to increase the amount of opioids you take over the past six months?" (OR 0.38; 95% CI, 0.16 - 0.88).

Conclusions: There is a high prevalence of people with life-limiting illnesses who do not routinely dispose of their opioids.

Abstract ID: P04:21**Abstract type: Poster****Content validity of the Utrecht Symptom Diary - 4 Dimensional from the perspective of healthcare professionals***T. Lormans*¹, *E. de Graaf*¹, *C. Leget*², *S. Teunissen*¹¹UMC Utrecht, Centre of Expertise Palliative Care Utrecht, Utrecht, Netherlands, ²University of Humanistic Studies, Care Ethics, Utrecht, Netherlands

Background/aims: The Utrecht Symptom Diary - 4 Dimensional (USD-4D) is a further development and integration of the Utrecht Symptom Diary and Diamond model. In palliative care, the USD-4D supports the identification, monitoring and discussion of both physical and psychological symptoms and social and spiritual needs. The social and spiritual items each reflect one of the five tension fields of the Diamond model. Although the USD-4D is used in clinical practice, it has not been fully validated yet. Therefore, this study aims to establish the content validity of the USD-4D from the perspective of healthcare professionals (HCPs).

Methods: Cross-sectional survey study based on the based on the Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN) criteria. Content validity was operationalized as: comprehensibility, relevance, and comprehensiveness. HCPs were eligible for participation when they provided care to patients in the palliative phase. The survey was widely distributed within professional associations of relevant healthcare professions: nurses,

doctors, social workers, and chaplains. Prior experience with the USD-4D was not required.

Results: A total of 601 HCPs answered the survey: 85% female, mean age 48 years, 53% nurses. More than 90% of respondents indicated that the USD-4D items were understandable and could be interpreted both socially and spiritually. The relevance of the items was also endorsed by more than 90% of HCPs. 49% of participants reported missing items in the USD-4D. All these items fitted the tension fields of the Diamond model.

Conclusions: This study shows that the USD-4D content is valid from the perspective of HCPs. HCPs find the social and spiritual items understandable and relevant. The social and spiritual items cannot be interpreted unambiguously, which means that discussing them is indispensable to discover the meaning behind the given scores and to see what load patients give to them, which is intended by the USD-4D.

Abstract ID: P04:22**Abstract type: Poster****The Promise of Bigger and Better International Qualitative Research? Learning From the Palliative Sedation Project***N. Preston*¹, *A. Harding*¹, *M. Van der Elst*², *C. Anucuta*³, *F. Hurducas*³, *A. Csikos*³, *C. Busa*⁴, *E. Pozsgai*⁴, *J. Hasselaar*⁵, *S. Payne*¹¹Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom, ²KU Leuven, Experimental radiotherapy, Leuven, Belgium, ³Hospice Casa Sperantei, Brasov, United Kingdom, ⁴University of Pecs Medical School, Hospice and Palliative Care, Pecs, Hungary, ⁵Radboud Medical Centre, Nijmegen, Netherlands

Background/aims: Qualitative research methods consist of a set of interpretative practices that rely on the integration of a set of shared values, beliefs and practices by which data are collected and analysed. When data is being analysed by groups of researchers this can become complex and even more so when research is conducted in different countries/languages.

Aim: To describe the process of developing shared analysis methods in international qualitative research.

Methods: We draw on the experience of undertaking qualitative research within the European Palliative Sedation project; 1) interviews conducted with bereaved families and healthcare professionals in clinical case studies in 5 countries, and 2) moral case deliberations with healthcare professionals in 8 countries. Framework analysis was selected to enable both within country and cross-country comparisons.

Results: We developed a topic guide for the data collection based upon the literature and expert knowledge. We used this as a guide to develop a provisional coding framework. We then tested the framework against a transcript to gain feedback from a small number of researchers including senior academics. This allowed for sense checking about how to apply codes and modification of codes. We then tested the framework with all researchers following two online training sessions. Minor modifications were made to guidance notes on how to apply the framework and some new codes added including country specific codes.

Conclusions: Challenges:

- Researchers have very different expertise and understandings of qualitative methods
- Most will be using English as a second language
- Risk of loss of semantic and nuanced meanings in translation
- Cultural norms that underpin what may or may not be asked in the context of interviews, especially on sensitive topics

Solutions:

- Training
- Collaborative development of coding frameworks

Using more structured approaches such as framework analysis improves shared understanding and application of analysis.

Abstract ID: P04:23

Abstract type: Poster

Improving the Methods for Patient Reported Experience Measures (PREMS) In Palliative Care: Findings From a Cognitive Interview Study
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Background/aims: Patient-reported experience measures (PREMs) are questionnaires designed for asking consumers about their experience of healthcare to inform service improvements. It is unclear how people with palliative care needs manage the cognitive demands of completing PREMs, or how this can be supported. This study aimed to explore cognitive operations among people with palliative care needs when completing a draft PREM in order to inform future methods.

Methods: A qualitative approach was taken, using cognitive interviews. Participants were people receiving inpatient or community specialist palliative care with stable disease who were not bedbound. Interviews used 'think aloud' and verbal probes to explore the four cognitive operations of comprehension, recall, judgement and response to a 33-item draft PREM, developed using a standard process employed by the New South Wales Bureau of Health Information. Analysis proceeded first within- and then cross-case to explore patterns.

Results: Fourteen people participated, all of whom had cancer except one with motor neuron disease. Seven discussed inpatient care, and seven community care. Participants encountered challenges with all four cognitive operations. Many participants were unfamiliar with end-of-life care concepts like declining treatment. Participants often struggled to remember, answered hypothetically, or digressed beyond the focal setting. Few participants used the mid-point on a 3-point scale. However, all participants could complete two open-ended items on aspects of care they regarded as 'best' or 'most needs improving'.

Conclusions: Palliative care patients find PREMs challenging to complete and require supports to improve the quality and interpretability of data. Pending further research, tentative suggestions are made for questionnaire design and administration.

Abstract ID: P04:24

Abstract type: Poster

Translation and Cross-Cultural Adaptation of the German IPOS Neuro-S8

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Background/aims: Little is known on how to best integrate palliative care for neurological patients, and there is a scarcity of outcome

measures for neurological patients in need of palliative care. The Integrated Palliative Outcome Scale for neurological patients in its short form (IPOS Neuro-S8) was developed for patients with progressive, long-term neurological conditions and helps assess and identify problems early and, if indicated, consult palliative care structures.

To culturally adapt and translate the IPOS Neuro-S8 to the German health care context and evaluate its face and content validity.

Methods: Cross-sectional, qualitative study following the first five phases of an established guideline: i) conceptual equivalence, ii) forward translation to German, iii) backward translation to English, iv) expert review, v) cognitive interviews. Patients currently receiving palliative or neurological care and health care professionals with extensive experience in either palliative care or neurology participated in the study. Data were analysed using thematic content analysis. Descriptive statistics were calculated using SPSS software.

Results: While patients (n=9) and health care professionals (n=11) confirmed that the IPOS Neuro-S8 is an intelligible tool that is well accepted, some linguistic and cultural differences were found between the original English and German versions. These mainly concerned the items mouth problems and spasms.

Conclusions: The German version of the IPOS Neuro-S8 has demonstrated face and content validity. The tool can capture the total symptom burden of neurological patients in need of palliative care. Its psychometric properties, including construct and criterion validity, will be investigated next.

Funding: This work was supported by the Innovation Funds of the Federal Joint Committee (G-BA), grant number 01VSF19029.

Abstract ID: P04:25

Abstract type: Poster

Qualitative Study of Paediatric Advance Care Planning Through Simulation: How We Did It and the Lessons Learned

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Background/aims: Simulation allows clinicians to experience a replication of reality, enabling feasible and ethical study of complex phenomena, such as communication and care around the end of life. There is a paucity of literature describing how to design a simulation as an investigative method in qualitative research. This work describes how we designed a simulation-based qualitative study exploring paediatricians' communication practices in paediatric advance care planning and our learnings about this research method.

Methods: Consistent with a phenomenological methodology, we designed a clinical simulation where individual paediatricians interacted with two actors playing the role of parents of a young child with a life-limiting condition. We observed each simulation behind one-way glass. Our observations informed individual post-simulation interviews of each paediatrician, and concurrent, separate interviews of both actors. Data were collected from the audiovisually-recorded simulation and the audio-recorded post-simulation interviews. Transcripts of these recordings were planned for conversational and content analysis, respectively.

Results: Our qualitative study design focused on: (i) simulation development, (ii) enhancing realism, (iii) promoting psychological safety of the paediatricians, (iv) pilot testing, and (v) measures to enhance credibility and trustworthiness of the analytic process that were possible because of simulation.

Conclusions: Simulation is a safe and viable research method in qualitative inquiry. Its utility in the research context is enriched by detail to

factors that enhance realism and it affords multiple opportunities to promote rigour. Pilot testing is essential and should include review of the quality of the audio-visual recordings, and the practice of data handling. Through simulation, rigorous research can be conducted into complex and sensitive phenomena that are of interest to palliative care researchers. This research will ultimately enhance the quality and delivery of care.

Abstract ID: P04:26

Abstract type: Poster

Ethical Challenges in the PICU: Adapting the Factorial Survey Approach to Identify Multiple Influencing Factors on the Decision to Initiate Technology Dependence

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Background/aims: The decision to initiate invasive long-term ventilation (ILTV) for a child can be an extremely challenging one for all involved. This methodological paper describes the development of one phase of a five-year programme of research that examines this important yet underexamined topic. Based on experimental vignette methodology, a factorial survey allows for random, yet systematic manipulation so that interchangeable levels of each (possibly influencing) factor can be examined in a controlled vignette.

Aim: Develop, pretest, and pilot a factorial survey that examines influences on the likelihood of a clinician to support the initiation of ILTV for a child.

Methods: Preliminary content was developed from literature reviews alongside factors identified from n=78 clinician interviews. Pretesting included: Clinical experts review; cognitive interviews; vignette population review; statistical consultant review; in-team usability testing. The self-administered online pilot study was completed with a convenience purposive sample from the target population. Institutional ethical approval was obtained.

Results: This work resulted in a 43-item tool that included two age-based sets of clinical vignettes, eight randomly presented per participant from a vignette population of 480. Possible factors identified in the development phase were extensive and the clinical literature guided initial refinement. Modifications following expert consultations and cognitive interviews included: Inclusion and reordering of additional clinical information; factor reduction; revision of language to suit an international audience. The pilot study confirmed feasibility in terms of ease of completion, completion time as well as feedback on content and response options.

Conclusions: Underreporting on the development stages of studies limits the development of similar work. More pretesting information improves ethical standards and design quality thereby serving to protect participants and increase trust in the research process.

Abstract ID: P04:27

Abstract type: Poster

Systematic Quality Measurement of Hospice Care - Lessons Learned From Implementation Process in the Czech Republic: A Qualitative Approach

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Background/aims: Any systematic tool to evaluate the quality of hospice care has been lacking in the Czech Republic. Based on the international literature and using the service provider's involvement approach, we have developed a set of quality indicators, combining data from a patient medical record, organizational data, and questionnaire survey for bereaved family caregivers. This study aims to analyze the implementation of our novel quality measurement tool, with a focus on the feasibility, content, and perception of the tool by the service providers.

Methods: The implementation of the tool was piloted over the period of 9 months in 5 hospices, 2 residential and 3 community services, operating in 4 regions. Data were collected from managers and staff members engaged in the implementation process. Two methods were used: semi-structured interviews (n=10) and three online workshops (n=6/4/8). All collected data were analyzed according to the principles of thematic analysis.

Results: The findings indicate that the quality measurement tool was well accepted. Following domains were assessed: (i) feasibility- a workload connected with the tool did not cause any staff resistance and the tool was perceived as suitable; (ii) content- the design was assessed as user-friendly but most participants suggested changes in the patient medical record form; (iii) service improvement- the tool helped service providers to identify areas relevant for service improvement such as changes in in-house documentation and communication with bereaved relatives.

Conclusions: The tool is seen as an appropriate and feasible approach towards improving the quality of hospice services. Although including service providers in the development and implementation process was challenging it was crucial for the acceptance and future service improvement.

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 ID: P04:28

Abstract type: Poster

Patient and Public Involvement – Contribution to the Development of an Survey Instrument

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Background/aims: Patient and public involvement (PPI) in the early stage of research e.g., during development of instruments is increasingly recommended by German Funding Resources, but how to assess its impact? **Aim:** Assessing the contribution of PPI to the development of a survey instrument addressed to nurses and physicians regarding team-based decision-making and communication in the event of serious illness and entry into the end of life care in a German Comprehensive Cancer Center.

Methods: Members of a PPI group of an academic palliative care department were invited to contribute to the development of a survey instrument by giving advice on comprehensibility, missing aspects and order. Involvement could be chosen by commenting on the survey instrument via email or participating in an online meeting of the research working group.

Results: Out of 22 invited members of the PPI group 5 individuals engaged after 10 days, 4 via email and 1 attended the online meeting. 20 comments were given on e.g., consideration of gender, order of items, formatting, wording like “relatives”, “usually”, “automatically”, “inadequate measures” and when questions judged as too formal (e.g., “It is checked/enquired whether the patient is aware of the approaching death”) or seemed to be not answerable in one answer option (e.g., “Please assess yourself and your team”). The research working group discussed all comments. 4 were not taken into account,

reasons were documented. 16 comments were accepted and the instrument adapted accordingly. PPI were informed about the changes made in the instrument and the reasons for those aspects that were not considered.

Conclusions: Having a PPI group in an academic palliative care department offers short-term support. The involvement was on consultation level in this case. Careful documentation allows to show the impact of the involvement.

Abstract ID: P04:29

Abstract type: Poster

Understanding the Role and Deployment of Volunteers Within Hospice and Specialist Palliative Care Services as They Have Adjusted to the COVID-19 Pandemic. A Multi-National EAPC Survey

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Background/aims: Data from early in the COVID-19 pandemic indicated a major decline in palliative care volunteer numbers and their support to service provision. This may impact on the quality and safety of palliative care service provision. The aim is to identify and understand the roles and deployment of volunteers in hospice and specialist palliative care services in the ongoing response to COVID-19.

Methods: Multi-national cross-sectional survey of hospices and providers of specialist palliative care services, using a convenience sample. A 68-item online questionnaire, aimed at people responsible for volunteer deployment, was disseminated via social media, palliative care networks and key collaborators from May to July 2021. Questions captured volunteer deployment pre-COVID-19, through the pandemic and future plans. Descriptive analysis and chi-square tests were conducted to compare results. Free text comments were analysed using content analysis techniques.

Results: Valid responses were received from 304 organisations (35 countries, 80.3% Europe). Most cared for adults only (60.9%), provided inpatient care (62.2%) and were non-profit (62.5%). 47.0% had cared for people with COVID-19. Volunteers tended to be younger than pre-pandemic. 47.7% changed the way they deployed volunteers; the mean number of active volunteers dropped from 203 per organisation to 33, and 70.7% reported a decrease in volunteers in direct patient/family facing roles. 50.6% said this drop impacted their organisation and care provision, increasing staff workload and pressure, decreasing patient support, and increasing patient isolation and loneliness.

Conclusions: The sustained reduction in volunteer deployment due to COVID-19 has impacted the provision of safe, effective palliative care. Urgent consideration must be given to the future of volunteering including virtual modes of delivery, micro-volunteering, and appealing to a younger demographic.

Abstract ID: P04:30

Abstract type: Poster

iLIVE Project Volunteer Study: Using a Newly Developed European Core Curriculum (Ecc) To Develop and Implement End-Of-Life-Care Volunteer Services Within 5 Hospitals Across 5 Countries

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Background: Across Europe palliative and end-of-life-care volunteer services (EOLC-VS) in the hospital setting are relatively uncommon, particularly for patients in the last weeks of life. The iLIVE Volunteer Study, one of 8 work-packages within the iLIVE Project, conducted an international Delphi study to develop a European Core Curriculum for EOLC-VC's, including associated training manuals. The ECC was designed to empower Volunteer Coordinators (VC's) to develop and implement EOLC-VS's in 5 hospitals in 5 countries, adapted to local cultural and organisational contexts. A case study to providing in-depth assessment of the facilitators and barriers in one hospital in the Netherlands has been undertaken (results reported elsewhere).

Aim: To support Volunteer Coordinators (VC's) to initiate EOLC-VS's in 5 hospitals across 5 European countries.

Methods: VC's attended a 3-day International Training Programme to examine and adapt the ECC implementation and training manuals to their individual organisational and cultural contexts. Due to COVID-19, virtual resources for support were engaged, including international networking sessions between EOLC volunteers and VC's. Structured feedback from VC's were collected at the 3-day training programme and throughout development, training of volunteers, and implementation of EOLC-VC's.

Results: The ECC provided VC's with a practical guide to design and implement EOLC-VC's within the complex environment of a hospital. The supportive resources gave VC's an opportunity to share learning, facilitating a deeper understanding of the ECC, as well as enable the sharing of practical experiences during service development and implementation using the ECC.

Conclusions: The ECC, with supportive resources, enabled successful implementation of hospital EOLC-VC's volunteer services across 5 countries. Further research to assess the use and experience of these services is now underway as part of the iLIVE Volunteer Study.

Abstract ID: P04:31

Abstract type: Poster

iLIVE Project Volunteer Study: Development and Implementation of an End-Of-Life Care Volunteer Service in a Dutch Hospital

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Background/aims: End-of-life care volunteering in hospitals seems promising but is uncommon, particularly for patients in the last weeks of life outside of specialized palliative care units.

Aims: To develop and implement an end-of-life care volunteer service in a Dutch hospital and to investigate the barriers to and facilitators of implementation.

Methods: In a descriptive case study, we collected and analyzed minutes of meetings including decisions made, plans for the structure of the service, logistical descriptions, volunteer training content. A European Core Curriculum (ECC), based on an international Delphi study, informed the design of the volunteer service, including a hospital palliative care volunteer training programme and a ten step model for implementation. The Consolidated Framework for Implementation Research (CFIR) was used to identify facilitators and barriers during implementation.

Results: The volunteer service started in March 2021 and is 24/7 available for inpatients with a chronic terminal illness in their last weeks of life at seven clinical wards. The main activities of volunteers involved being present and conversation.

Facilitators during implementation included explicit support from the management level, information materials for healthcare staff including a video for nurses about the volunteer service and a road map to inform patients. Volunteers considered supervision sessions about their experiences useful. Barriers included a short stay of patients in the hospital and disagreements within the project team on roles and responsibilities regarding implementation of the volunteer service.

Conclusions: Knowledge and tools to support planning, organizing, and continuous learning of volunteers are valuable for successful implementation of volunteer services for end-of-life care in other hospitals.

Abstract ID: P04:32

Abstract type: Poster

Discussing the Spectrum of Advance Care Planning in “The End of Life Big Room” - which Component to Prioritise in Hospitals?

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Background/aims: Advance care planning (ACP) is a process of discussion which focusses on individual wishes, goals, and priorities for care. ACP can be a spectrum of discussions based on anticipated prognosis and tailored according to an individual’s circumstances:

- Future care planning – over 2 years prognosis, including those with long term co-morbidities
- Urgent care planning – individuals with a prognosis of under 1-2 years
- End of life care planning – terminal prognosis– last months or weeks of life

This study aimed to establish agree a priority area within the spectrum of ACP for a large multi-centre urban hospital organisation.

Methods: A multi-disciplinary panel of clinical and lay experts attended an End of Life “Big Room” where a medical researcher presented evidence from interviews with older patients and their carers on views of ACP at the hospital, in addition to wider views of the general public on ACP. This was followed by a question-and-answer session with the panel. Attendees were invited to select the relevant parts of the spectrum of ACP which they thought should be given priority: future care planning, urgent care planning and/or end-of-life care planning.

Results: The Big Room voted to focus on future care planning as a first priority area. The panel found that in clinical practice, individuals have varying interpretations of what ACP involves, with inpatient staff focused on treatment escalation plans, resuscitation status and end-of-life care. It crucial to check individual’s understanding of ACP terminology and what people wish to discuss, including whether they wish to know about prognosis as part of understanding their medical condition.

Conclusions: ACP is welcomed by multi-disciplinary professionals as part of holistic care. ACP should be encouraged earlier for individuals, through future care planning, particularly for older patients with chronic conditions whose health is deteriorating, rather than leaving it to the final stages of life.

Abstract ID: P04:33

Abstract type: Poster

Integrating Palliative and Oncology Care – What Do Health Care Professionals Think Is Important for Developing a Holistic Model of Care?

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Background/aims: Integrated palliative and oncology care for cancer patients results in better quality of life, symptom control and survival. However, it is unclear how best this integration should occur, especially in the Asian setting where palliative care is less culturally accepted.

Our study team developed a novel model of integrated oncology and palliative care, where palliative care professionals joined the oncology team as *integrated team members* in the inpatient setting to *co-round and manage the patient’s issues collaboratively*.

The aim of this study was to understand the core components of an effective model of integrated oncology and palliative care and the impact of contextual factors on this model.

Using these findings, we will derive a logic model that illustrates these core components and allow for fine tuning of subsequent iterations.

Methods: Doctors, nurses, patients and their caregivers will be recruited for semi-structured interviews regarding their views towards components that contribute to a holistic and effective model of integrated care. Interview topics are structured according to the Consolidated Framework for Implementation Research Framework. Interview transcripts will be coded and analyzed via thematic analysis.

This abstract will report on the preliminary findings from interviews of *healthcare professionals*.

Results: Thus far, we have recruited 13 healthcare professionals – 10 physicians, 3 nurses. Seven of the staff participated in the co-rounding model, whilst six staff did not. The mean number of years working as a healthcare professional was 18.7 years.

The main themes from healthcare professionals included that of (1) team-work – defining leadership and roles of members (2) adequate resourcing (3) having an open and collaborative culture (4) relationship building within the team (5) mutual education.

Conclusions: There are core components that can be used to derive a logic model that can influence the building of an integrated palliative-oncology model.

Abstract ID: P04:34

Abstract type: Poster

Multidisciplinary Approach Implementation in a European Comprehensive Cancer Center

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Background/aims: The multidisciplinary approach is a fundamental component in the integration of oncology and palliative care and is now considered “best practice” in oncology. Multidisciplinary team working (MDT) can be broadly classified into Multidisciplinary Cancer Clinics (MDCC) and Multidisciplinary Tumor Board meetings (MDTB) (the former involving also patients), yet they are implemented following heterogeneous models.

Within a wider project on the impact of a model of MDCC for advanced cancer patients, this study aims to describe the different MDT models implemented in a comprehensive cancer center.

Methods: Structured interviews to clinicians were carried out to investigate MDT type, aims, team composition, disease phase, use of patient reported outcome/experience measures (PROMs/PREMs), and inclusion in a pre-defined care pathway. Descriptive analyses were performed.

Results: 38 structured interviews (13 MDCC and to 25 MDTB) were carried out. Responders were surgeons (15), oncologists (12), nurses (3) and other (8). 11 were the team leaders. MDTs are mainly aimed at sharing decision making with colleagues (54% MDCC, 75% MDTB) and optimizing patient care process (38%, 58%). MDTs are directed at patients in both early and advanced disease stage, but only a minority of them is included in a care pathway (42%, 32%). Teams are mostly composed of physicians only (69%, 64%), with an average of 3.5 members involved.

Clinical case-managers (31%, 8%), palliative care specialists (23%, 12%) and psychologists (31%, 20%), are limitedly involved, also when dealing with advanced disease. PROMs/PREMs are seldom used (23%, 24%).

Conclusions: Among the objectives, few MDTs report improvement in outcomes and responses to patients' needs. Despite a high number of MDCCs and MDTBs for advanced/metastatic disease, there is limited involvement of Palliative Care and Psychology. Physicians participation is prevalent and, overall, MDT implementation does not reflect patient centredness.

Abstract ID: P04:35

Abstract type: Poster

Palliative Healthcare Professionals Prefer Advice From a Prognostic Algorithm Rather Than Another Professional When Prognosticating Imminent Death in Advanced Cancer Patients: The ADJUST Study

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Background/aims: A second opinion or a prognostic algorithm may help ensure prognostic accuracy. However, it is unexplored how healthcare professionals (HCPs) integrate prognostic advice from colleagues or algorithms.

This study assessed the level to which HCPs integrate advice from either another HCP or a prognostic algorithm into their prognostic estimates, and how participants' profession and experience could impact this.

Methods: An online double-blind randomised control trial using 1:1 allocation ratio (ClinicalTrials; NCT04568629) was conducted.

Palliative doctors, nurses and other types of HCPs were randomised into study arms differing advice source (algorithm or HCP). They reviewed five patient summaries, each involving three steps: provide initial probability estimate of 2-week survival (0% 'certain death' – 100% 'certain survival'); receive advice according to study arm; provide final estimate.

Weight of advice (WOA), representing advice integration, was calculated per summary (0 '100% advice discounting' – 1 '0% discounting'). Multilevel linear regressions were conducted to compare mean WOA scores between study arms and to explore the interaction between study arm and participants' profession and experience.

Results: 283 HCPs were included in the analysis.

The algorithm arm had a higher WOA than the HCP arm (WOA difference = -0.12 [95% CI -0.18, -0.07], $p < .001$). "Other type" HCPs had a higher WOA (0.50 [SE 0.04]) than nurses (0.39 [SE 0.02]) and doctors (0.34 [SE 0.02]). However, there was no interaction between profession and the study arm on the WOA ($p=0.150$). HCPs with 15+ years of experience had a slightly higher WOA score (0.38 [SE 0.02]) than those with less experience (0.36 [SE 0.02]). There was no interaction between experience and the study arm on WOA ($p=0.935$).

Conclusions: HCPs integrate advice more if it comes from a prognostic algorithm rather than from another HCP. Profession and experience do not have an impact on advice integration.

Funding: PhD Studentship, Marie Curie Chair (ref: 509537)

Prof Patrick Stone and Dr Victoria Vickerstaff were involved in conducting the PiPS2 study that involved validating the PiPSB-14 prognostic algorithm that were used for this study.

Abstract ID: P04:36

Abstract type: Poster

Multidisciplinary Quality Improvement (QI) Project: Discharge Planning Checklist for Purpose of Patient Transfer From Hospice to Home

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Background/aims: Background: Patients with a life limiting illness frequently have complex care needs, thus discharge from hospice to home requires effective integrated discharge planning. Analysis of previous discharges highlighted shortcomings in discharge planning for patients who were discharged home for end of life (EOL) care and also following symptom control admissions.

Aims: The objective of this checklist is to facilitate a safe, efficient and smooth transition of care for all patients from hospice to home. The aim is to confirm that equipment, home supports and medications are all in place prior to discharge along with provision of information to patients, families and carers. This checklist also aims to ensure that effective verbal and written communication takes place between health and social care professionals working in the hospice and also community.

Methods: Areas for improvement were discussed with different stakeholders including; hospice nurses, doctors, pharmacists, occupational therapists, social workers, physiotherapists, community based palliative care nurses, general practitioners, patients and their families and carers. The recommendations regarding rapid discharge home for EOL as per the Irish National Clinical Program for Palliative Care 2018 were also reviewed. QI methods employed include; stakeholder map, process map, root-cause analysis, the 5 whys and plan-do study-act (PDSA) cycles.

Results: QI methodologies revealed that deficiencies in integrated discharge planning were due to ineffective verbal and written communication amongst hospice staff and also amongst hospice and community staff. It was decided that a discharge checklist would address these deficiencies. This was implemented in August 2021 and refined following multiple PDSA cycles.

Conclusions: This project utilised a multidisciplinary quality improvement approach to design a discharge checklist which enhances integrated discharge planning from hospice to home.

Abstract ID: P04:37

Abstract type: Poster

Patient and Public Involvement and Engagement in Research: An Example From a Mixed-Methods Study in Palliative Care

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Background/aims: High quality patient and public involvement and engagement (PPIE) ensures that research is effective, representative, and focused on patients' needs.

Aims: To describe PPIE activities and their impact in a palliative care study.

Methods: The six UK Standards for Public Involvement were used to evaluate PPIE activity in a single site mixed-methods observational study.

Results: *Inclusive Opportunities:* Early involvement of PPIE through the local Patient and Carer Research Review Panel.

Working Together: Co-design: PPIE members influenced the addition of the qualitative element. Co-production for meaningful collaboration: PPIE member is being co-applicant on research grant and co-investigator. Involvement in writing the patient-facing documentation, plain language summary, study protocol and funding application. Attendance at the Research Ethics Committee meeting. Involvement in qualitative data review and development of themes.

Governance: PPIE in the Trial Management Team and Trial Steering Committee.

Communication: Continuous involvement and engagement maintained (face to face/virtual meetings and emails) and PPIE contribution to dissemination (conference and journal publications).

Support and learning: PPIE organisational infrastructure with a dedicated PPIE lead and training opportunities. Dedicated bespoke PPIE digital platform enables involvement. Discussions about end-of-life were challenging for some members.

Conclusions: Impact and lessons learned: PPIE increased the effectiveness and credibility of this study and raised awareness of PPIE in palliative care. Specific challenges but also drivers for PPIE within palliative care research include the vulnerability of participants and PPIE members and the subject matter (end of life, advanced cancer, palliative versus curative dichotomy). Adequate funding, training about palliative care research and virtual meetings can facilitate engagement. Institutional leadership supports successful PPIE involvement in studies.

Abstract ID: P04:38

Abstract type: Poster

What Matters? Using Creative Activities to Develop Research Ideas With Lay Participants

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Background/aims: Creative activities can help to reduce linguistic barriers and facilitate broader discussions in end-of-life care. We designed a series of creative activities, aiming to engage people with advanced disease and their carers (current and bereaved) in developing research proposals and priorities.

Methods: We identified participants through local and national clinical and research networks. We formed separate groups for each type of participant to enable open discussions. The activities, using visual imagery and creative tasks, took place during two two-hour sessions, one week apart. Each participant received a package of words, images, creative materials, and refreshments, and attended online or in-person.

Session 1 progressed from discussing the words and images to what was important to participants, any related experiences they wished to share, and wider end-of-life discussions.

After Session 1 participants were set the task of using the materials sent, or any other medium, to create something relating to what mattered to them regarding the end of life.

Participants were all added to a MS Teams group where they were able to chat, share, and discuss with us and each other.

Session 2: Participants presented and discussed what they had made. We then presented on one of two research proposals, and solicited their feedback on both.

Results: Analysis is ongoing. We will present some of the themes identified including: guilt, forgiveness, and family dynamics, and how this work informed our research proposals. We will share the images (with permission) that participants created, and present their feedback on their participation and the events.

Conclusions: Using creative activities to engage lay people in research possibilities, enabled wider reflection on issues that are not well anticipated, recognised or discussed, and enriched and strengthened our proposals.

Abstract ID: P04:39

Abstract type: Poster

Feasibility and Safety of Exercise With Patients Suffering From Advanced Pancreatobiliary Cancers (aPBC) Receiving Beyond First-Line Chemotherapy With and Without Exercise Therapy (P-Move)

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Background/aims: Patients (Pts) with advanced pancreatobiliary cancers (aPBC) frequently suffer from high symptom burden. Studies of curative treatments indicate that exercise can reduce treatment side effects and improve patient-related outcomes (PROMs). However, evidence from prospective studies in the palliative settings is rare. The primary aim of the prospective, randomized-controlled study P-MOVE is to evaluate the feasibility of exercise therapy (ET) in patients with aPBC beyond first-line chemotherapy.

Methods: 40 Pt (Stage III/IV) will be recruited beyond first-line therapy. Pts are randomized according to the minimization procedure with strata: gender, age and loss of body weight past six months. The intervention group (IG) completes 3 training units per week for 8 weeks (1x supervised strength training, 2x individualized home-based trainings weekly). Control group (CG) receives recommendations on daily activities. Analysis followed the intention to treat principle. In addition per protocol analysis with 75% completed exercise sessions will be carried out.

Results: Since study initiation, 100 Pts were screened within the first year. Of those 70 Pts did not meet eligibility criteria. Of 30 eligible Pts, 20 have been recruited (66.7%). Reasons for not participating were distance to study center (n=5), clinical deterioration or death during screening period (n=3) and no interest in ET (n=2). The drop-out rate was 30% (3 in IG and 3 in CG). Main reasons for drop-out were reduced general condition due to disease progression (n=5) and cancer-related death (n=1). Adherence to ET in total was 125/166 (75.3%) and 75/106 (70.8%) for unsupervised ET sessions. No adverse events related to ET were reported. Statistical comparison of PROs will be provided with higher patient enrollment.

Conclusions: Preliminary data suggest that ET beyond first-line palliative treatment in Pts with aPBC appears feasible and safe yet challenging.

Abstract ID: P04:40

Abstract type: Poster

The Palliative Care Outcomes Collaboration (PCOC) Audits in Practice

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Background/aims: The PCOC framework helps to initiate and support clinical assessment in palliative care, and creates a common language to aid planning and delivering care. PCOC framework is in various stages of implementation in Ireland.

Methods: Four separate audits to assess compliance with PCOC framework were completed in a specialist palliative care inpatient unit between August and October 2021. These were 1) Response to PCOCs assessment 2) Phase definition 3) Phase assessment and 4) Palliative Care Problem Severity Score (PCPSS) audits.

Results: The Response to PCOC audit demonstrated poor compliance in completion of PCOC assessment on admission (35%), discharge (52%) and daily (5%). Satisfactory compliance was achieved for all audit items triggering an escalation in care (e.g., decreasing AKPS scores, unstable phases recorded, significantly increasing RUG-ADL scores, SAS scores in the severe range and scores of moderate or severe PCPSS).

The Problem Severity Score (PCSS) audit demonstrated moderate inter-rater reliability when assessing problem severity in the 'psychological/spiritual' and 'other symptoms' domains, and good inter-rater reliability when assessing 'family/carer' distress (90% congruence). Significant inter-rater variability was demonstrated when assessing patients pain scores with only 30% congruence between clinicians.

The appropriate palliative care phase definition was attributed in 61% of cases. Recording a phase as *stable or deteriorating* instead of *unstable* contributed to poor compliance. Inter-rater consensus when assessing the patient phase was demonstrated 60% of the time.

Conclusions: Results demonstrate the need for improvement in various PCOC assessments. Results are being rapidly disseminated to staff and re-audit will be commenced within 3 months. Educational material including the official PCOC training programme will be highlighted to staff engaging in PCOC assessments.

COVID-19

Abstract ID: P05:01

Abstract type: Poster

'Under Extraordinary Circumstances'. Qualitative Analysis of Medical Students' Experiences in Caring for Palliative Patients during the COVID-19 Pandemic

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Background/aims: For medical students the COVID-19 pandemic significantly impacted both their personal as well as their academic life. Responses with regard to medical education during the pandemic ranged from restricted patient contact for medical students to integration of students into the health workforce as volunteers. This study aims to explore medical students' experiences of caring for palliative patients during the COVID-19 pandemic.

Methods: As mandatory part of the palliative care curriculum at a German medical school, 5th-year students wrote two short reflective essays on their experience with palliative patients. We electronically searched all essays submitted between 27.1.2020 and 26.10.2021 for the following key words: 'Cov', 'SARS', 'Corona' and 'pandemic'. Essays that described students' clinical experiences during the COVID-19 pandemic were then analysed using qualitative content analysis.

Results: From 1276 essays screened, 115 essays written by 103 students met the inclusion criteria. Analysis revealed five main themes: 'psycho-social impact of visitation restrictions', 'challenges in end-of-life decision-making', 'reduced provision of palliative and psychosocial care', 'emotional impact on health care workers (including students)' and 'experiential-reflective learning'. The first three topics refer to the impact the pandemic had on patient care, while the latter two refer to the students' personal reactions to these experiences.

Conclusions: Analysis of students' essays provided insight into two aspects: 1) the challenges of providing patient-centered care for terminally ill patients during the pandemic and 2) how these experiences affected medical students emotionally and professionally. For some students, these experiences lead to a reflection of dignity in dying and the relevance of psycho-social-spiritual aspects in end-of-life care and may shape their professional identity. Medical educators should address these formative experiences to support students in their growth as future doctors.

Abstract ID: P05:02

Abstract type: Poster

Withdrawal of Non-invasive Respiratory Support (CPAP) in Critical Care

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Background/aims: Palliative care has been an integral part of the COVID-19 response. Timely removal of CPAP for dying patients can offer a dignified and comfortable death but can be a daunting process.

Aim: To improve the withdrawal of non-invasive respiratory support (CPAP) for palliative patients in critical care

Methods: This project was undertaken in three parts and involved junior doctors and nursing staff within the critical care department. The first part used questionnaires to assess staff experiences and confidence in withdrawing CPAP. A scale was used to assess confidence with 0 = no confidence to 5 = full confidence. The second part entailed focussed teaching sessions for staff members. Pre and post teaching questionnaires were used to assess the impact on staff confidence. Finally, a CPAP withdrawal guideline based on a literature review, was created; with steps for preparation, medicine administration and oxygen titration. Feedback was collected from staff that used the guideline for patients in the unit.

Results: The first part identified that 65% of participants (n=23) had experiences of withdrawing CPAP and all found these difficult. Most staff said they lacked confidence in this process (56.4% rating themselves as 3 or less). 95.7% of staff wanted teaching and stepwise guidelines to follow. Teaching demonstrated an improvement in staff confidence (n=8), from 65.2% rating themselves as 3 or better to 100%. Following the use of guidelines, staff (n=2) rated their confidence as at least 3 and rated the protocol as mostly easy to follow. 100% staff deemed a stepwise approach to withdrawal as useful.

Conclusions: Most critical care staff do not feel confident in withdrawing CPAP for dying patients despite the importance of this process, especially in the COVID-19 pandemic. Our project makes steps towards improving this aspect of care and we advocate for teaching to support staff. We will continue to evaluate the withdrawal guidelines within our department as we care for patients with COVID-19 and beyond.

Abstract ID: P05:03

Abstract type: Poster

Support for Relatives of Patients Admitted to Intensive Care Units in the Netherlands Before and During the COVID-19 Pandemic

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Background/aims: During the first COVID-19 wave intensive care unit (ICU) visits of relatives were highly restricted in the Netherlands. Frequent contact with relatives of patients is a vital pillar of normal ICU care. Yet, the pandemic forced ICU teams to considerably modify their communication with relatives.

Therefore, interventions including regular telephonic updates by medical (ICU and non-ICU) staff, social and spiritual workers, were started to support the relatives.

Aim: Examine to what extent relatives of ICU patients with COVID-19 felt supported during the first COVID-19 wave in six Dutch ICUs and how this

differs from experiences of relatives of patients at these ICUs before the pandemic.

Methods: A written survey among first contact persons of ICU patients:

- 1) with COVID-19 during the first wave (t_1 : 15-3-2020 – 15-5-2020), and
- 2) with mechanical ventilation pre-COVID-19 (t_0 : 1-12-2019 – 31-1-2020) including items of the validated ‘Consumer Quality Index – relatives’ and an item on emotional support. Differences between t_1 and t_0 were tested using logistic regression analyses.

Results: Relatives of t_1 ($n=130$; response 71%) and t_0 ($n=94$; response 61%) were equally positive in regard to receiving comprehensible information, receiving contradictory information, feeling taken serious by professionals, having a voice in decision-making, having enough time for questions during decision-making, and being offered emotional support. Interestingly, relatives of t_1 were compared to those of t_0 significantly more positive ($p<0.05$) about professionals having enough time for support (t_1 : 92.1%; t_0 : 80.2%) and listening carefully (t_1 : 96.1%; t_0 : 88.9%).

Conclusions: The interventions during the first wave were able to offer similar levels of support to relatives as before COVID-19; on some aspects support was more favorably evaluated. The results give pointers for how to best support relatives in future pandemics and in “normal” situations.

Funding: ZonMw (844001801)

Abstract ID: P05:04

Abstract type: Poster

SARS-COV-2 Control Measures in Specialised Inpatient Hospice and Palliative Care in Germany – A Nationwide Survey on Challenges and Solutions

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Background/aims: Impact of the federal government’s restrictive lockdown (LD) policies on inpatient hospice (IH) and palliative care (PC) teams. To track challenges for and solutions of IH and PC providers during the LDs in Germany.

Methods: Semi-structured expert interviews with 12 hospice and PC experts to develop themes for a nationwide survey. Qualitative data were coded thematically, quantitative survey data were analysed descriptively.

Results: A total of 37% (adjusted $n=216$) of PC units ($n=102$), IH ($n=86$) and hospital PC support teams ($n=28$) participated in the survey in 02/2021. Restructuring took place in all facilities surveyed. Some PC units were closed or relocated into other units during the 1st LD, resulting in decreased admissions and financial imbalances. Follow-up care was (very) difficult to organise for 70% of PC units/hospital PC support teams. For IHs, building structures made it difficult to set up areas for quarantine or isolation. Saying farewell to dying patients infected with SARS-COV-2 was not possible in 34%/24% of PC units during the 1st/2nd LD. Saying farewell to non-infected deceased was allowed with restrictions. Alternative memorial rituals included memorial walks, joint devotional hour in different locations. Visiting restrictions were a particular challenge for staff (78%/2nd LD). Loss of family caregiver support was a huge burden (PC units 66%/2nd LD, IH 58%/2nd LD). Teams were extremely burdened by observance of distance rules, loss of closeness to patients and their relatives, lack of time for rituals, and increased work constraints.

Conclusions: LD policies and legislation had a great impact on care provision. Many facilities found solutions to live their approach despite the restrictions.

Funding: German Federal Ministry for Education and Research, no. 01KX2021.)

Abstract ID: P05:05

Abstract type: Poster

“Into the Fire”: A Focus Group Study of Redeployed Staff During the COVID-19 Pandemic

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Background/aims: During the COVID-19 pandemic, redeployed staff whose services were temporarily suspended were offered a range of opportunities for work to support efforts to manage the impact of the pandemic. A new team known as the “Cygnet” was established within an existing team to provide non-specialist end-of-life and bereavement care during the COVID-19 pandemic. 72 redeployed staff opted into this team. It is important to evaluate new services and one important component of this is understanding the perceptions of those staff who took on the new role.

Objectives: To evaluate the service from the perspectives of staff

Methods: Design: Focus group study

Setting: One large, combined acute NHS Trust in Northern UK incorporating 4 hospitals

Participants: A purposive sample of fourteen NHS staff who had worked as Cygnets during the COVID-19 pandemic

Methods: Three focus groups. Transcribed and anonymised. Data analysed using Braun’s approach to thematic data analysis.

Results: Participants opted in to the role from a wide variety of clinical and non-clinical backgrounds, with great diversity in terms of prior experience of end of life care. Reasons for volunteering were both professional (for example, career development) and personal (for example, pre-existing anxiety around death and dying). Participants considered that overall, they had benefited on personal and professional levels from taking on the Cygnet role, and that this had been a learning experience in terms of knowledge, skills and attitudes. Challenges identified included those related to the broader emotional climate resulting from the rapidly intensified demand for end of life and bereavement support against a backdrop of restricted family visiting.

Conclusions: This was a rapid response to a need for increased provision of compassionate end of life care and was a beneficial experience for staff. More research is required into the broader value of the non-specialist end of life care companion role within the hospital infrastructure.

Abstract ID: P05:06

Abstract type: Poster

Patients’ experiences with virtual outpatient palliative care visits during the COVID-19 pandemic: a qualitative study

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Background/aims: Early palliative care, delivered in oncology palliative care clinics (OPCCs) typically involves in-person visits. The COVID-19 pandemic necessitated rapid changes in the delivery of ambulatory care, and the adoption of virtual care where feasible.

Aim: To determine the experiences of patients who switched from in-person to virtual visits to an OPCC at a tertiary cancer centre in Toronto, Canada during the COVID-19 pandemic.

Methods: One-on-one telephone interviews were conducted with patients who had at least one in-person visit to the OPCC prior to the COVID-19 pandemic, and whose subsequent follow-up was switched to virtual visits. Purposive sampling was used to ensure representation based on sex, age, distance from their home to the cancer centre, and mode of virtual visits (telephone versus video). Interviews

were recorded and professionally transcribed; thematic analysis was used.

Results: Sixteen patients were interviewed, lasting between 20-60 minutes. Patients reported overall ease with the transition to virtual care, and appreciated that virtual care allowed for continuity of care without disruption during the pandemic. Previous in-person visits to the OPCC were felt to be advantageous in terms of rapport-building with the team, especially for the initial visit; non-verbal communication was highlighted. Many participants expressed a desire to have the option for virtual care beyond the pandemic, especially during periods of relative health stability.

Conclusions: Virtual visits to the OPCC during the COVID-19 pandemic were feasible and appreciated by patients. The role of virtual care for select clinical scenarios beyond the pandemic should be further explored.

Abstract ID: P05:07

Abstract type: Poster

Decrease in Pain Perception During Acute SARS-CoV-2 Infection: A Case Series

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Background/aims: Many reports have described pain appearance or an increase of chronic pain concomitant to SARS-CoV-2 infection. Here, we describe the cases of three patients with chronic cancer pain, in which COVID-19 was associated with a dramatic reduction/disappearance of pain.

Methods: Descriptive report of three oncological patients with chronic pain hospitalized in the context of acute COVID-19. Clinical information was personally retrieved by the authors, who also examined the patients. Brain MRI was performed when deemed necessary by the referring physician. Autopsy, when conducted, was performed at the request of family members. All three patients were hospitalized between October 2020 and January 2021.

Results: In this case series we describe, for the first time, a group of patients with chronic oncological pain, in which severe SARS-CoV-2 infection resulted in a temporary decrease of pain perception. It should be noted that despite optimal treatment, pain was insufficiently controlled in all cases prior to the infection. Patient 1 suffered from medullary compression at D2 due to probable perivertebral metastasis associated with bone lysis; patient 2 suffered from painful rib metastases; patient 3 suffered from neoplastic infiltration of the rectum from a bladder adenocarcinoma. None of the patients had impaired cognitive function that could have compromised their evaluation of pain. None of the patients complained of dyspnea at the moment of hospitalization; moreover, the reappearance of pain in patient 3 coincided with recovery from COVID-19 and de novo onset of dyspnea.

Conclusions: To our knowledge, this is the first case series reporting an acute reduction in pain perception in COVID-19. We believe further investigation is mandatory, as it could shed new light on the mechanisms of pain perception and modulation.

Abstract ID: P05:08

Abstract type: Poster

COVID-19 vs Primary Lung Disease: Comparison of Symptom Management Requirements at End of Life

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Background/aims: In early 2020 as the COVID-19 (C-19) pandemic hit the UK, it was anticipated patients dying of C-19 would experience severe and distressing symptoms at end of life. Specific guidance was developed, in addition to established Scottish Palliative Care Guidelines, to advise on managing symptoms of those imminently dying of C-19. We sought to determine whether medications administered to those dying of C-19 differed to those administered to those dying of other primary lung disease (PLD).

Methods: Case notes and electronic prescriptions of patients who died in hospital over a seven-week period in 2020 with a primary diagnosis of C-19, known to the hospital specialist palliative care team (HSPCT) were analysed and compared with data from patients with PLD in a similar period in 2019, known to the same HSPCT.

Results: 34 patients with C-19 compared with 26 PLD patients (88.5% respiratory malignancy, 7.7% COPD and 3.8% bronchiectasis). Mean age 76 years vs 71. Average time from admission to referral 8 vs 6 days, time to death average of 2.7 vs 7 days from point of referral. Both groups experienced an average 2.4 symptoms with most common being dyspnoea (76.5% vs 69.2%), pain (73.5% vs 65.4%), agitation (38.2% vs 42.3%) and respiratory secretions (38.2% vs 38.5%). Medications in 24 hours prior to death for C-19 group: morphine equivalent daily dose (MEDD) average 20.4mg versus 62.4mg, midazolam 8.8mg vs 5.8mg, levomepromazine 12.5mg vs 6.25mg, hyoscine butylbromide 60mg vs 100mg. The MEDD in the C-19 group was higher, but increase since admission was 10mg in both groups.

Conclusions: Similar symptoms experienced in both groups with possibly more complex symptom control in PLD. C-19 patients had greater requirement for anti-agitation medication while PLD patients had greater opioid requirements. Higher opioid dose in PLD patients secondary to long term symptom control, however average opioid requirements increment by same amount. Doses in C-19 were within the range of established guidelines.

Abstract ID: P05:09

Abstract type: Poster

'It's There, It's in Front of Your Face if You Put On the Radio or the TV': COVID-19, Perceptions of Death and Dying and the Context of Public Engagement

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Background/aims: The COVID-19 pandemic has brought conversations about death and dying to the fore. Prior studies indicate that holding conversations about the future and end of life planning is beneficial but can be very difficult. Therefore, it is important to identify how the pandemic may have affected the conversations people have had, or would want to have, and the potential role of public engagement in that context. The study had two aims: 1) to understand the publics' experiences of participating in conversations about death and dying, and the impact of COVID-19 on those conversations, and 2) to examine the role of public engagement and citizen science in end of life care, death and dying.

Methods: A scoping review of the health and social sciences literature was conducted to identify relevant citizen science and public engagement projects. Individual semi-structured interviews (n=12) were conducted with public volunteers between June and August 2021 and analysed using thematic coding.

Results: The qualitative interview data generated nine main themes which included the triggers, barriers, and benefits to conversations about death and dying; and the influence of personal factors, such as age. Moreover, the impact of COVID-19 in prompting thinking and conversations about death and dying was clear. The predominance of social dialogue around COVID-19 was reported as beneficial in encouraging useful conversations, however sadness was apparent at those

conversations that had not been possible in the pandemic. The scoping review identified 33 articles and numerous public engagement projects, but found no evidence of a citizen science project entirely focused on death or dying.

Conclusions: The role of the COVID-19 pandemic in thinking about death and dying was clearly evidenced. Numerous examples of public engagement activities were also identified. However, both the interview and scoping study data highlight the sensitivity of the subjects, and opportunities and constraints in discussing death and dying openly.

Abstract ID: P05:10

Abstract type: Poster

COVID-19 Related Experiences in a Spanish National Sample of Palliative Care Professionals

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Background/aims: COVID-19 pandemics has been a real challenge for palliative care professionals. They have been exposed to the front line of the pandemics, and have suffered from the lack of access to adequate protective equipment; the feeling of inadequate support; prolonged working hours and unexpected changes in the type of work; the concern about becoming infected or infecting their relatives; the lack of access to updated information on constantly changing guidelines for action; or the uncertainty about disease containment. Additionally, COVID-19 has been a challenge for patients' dignified deaths.

The aim of this research is to describe COVID-19-related experiences have affected Spanish palliative care professionals during the pandemics.

Methods: This study has a cross-sectional design. Data of 241 Spanish palliative care professionals were gathered after one year of COVID-19 pandemics (April-May, 2021). Analyses included descriptive statistics.

Results: 32% of the professionals (n= 77) reported absence of adequate protective equipment during the pandemics. More than a half (58.5%; n= 141) declared a significant increase in their workload during the pandemics, and more than 40% reported a deterioration in the teamwork. Almost all the participants had treated COVID-19 patients during the pandemics (89.6%; n= 215). Out of them, 192 reported patients dying with COVID-19. In these cases, only 83 (43.9%) reported that the death process of COVID-19 patients has been accompanied by a family member, and 62 professionals (32.6%) felt that adequately accompanied their COVID-19 patients in their dying process and that they had a dignified death.

Conclusions: COVID-19 pandemics has affected both the quality of work and the quality of care of Spanish palliative care professionals. Patients' dignity in the dying process was not accomplished according to the perception of one in three professionals.

Abstract ID: P05:11

Abstract type: Poster

The Role of Training in Palliative Care Professionals When Facing Burnout in Times of COVID-19

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Background/aims: Palliative care training has arisen as a protector of professionals' burnout. Also coping with death has repeatedly been

related to burnout, with higher levels in such a competence resulting in lower levels of burnout. In this same line, stress management training, in its different forms, has also been related to lower levels of burnout. Because the COVID-19 pandemics has increased the risk of burnout in palliative care providers, the role of education and training as protectors is of interest.

The aim of this research is to describe how training was related to palliative care professionals' burnout during the COVID-19 pandemics.

Methods: This study has a cross-sectional design. Data of 241 Spanish palliative care professionals were gathered after one year of COVID-19 pandemics (April-May, 2021). 224 professionals reported their levels of burnout.

Results: 86.16% professionals reported having received specific training in palliative care, 74.55% in coping with death, and 62.95% in stress management. 23.2% of professionals suffered from high emotional exhaustion, 39.0% reported high depersonalization, and only 17% informed of low personal accomplishment.

When burnout was related to training, higher levels of depersonalization and lower levels of personal accomplishment were found in those who did not received specific palliative care training, compared to those who did. Those who had received coping with death training showed lower levels of burnout, in the three dimensions: lower emotional exhaustion, lower depersonalization, and higher personal accomplishment. Finally, stress management training did also affect professionals' levels of burnout: professionals who had received such training reported lower levels of emotional exhaustion and depersonalization.

Conclusions: Training in palliative care, coping with death, and stress management have protected Spanish palliative care professionals from suffering burnout during the pandemics.

Abstract ID: P05:12

Abstract type: Poster

The Impact of Advance Care Planning on Place of Death During the COVID-19 Pandemic: Retrospective Cohort Analysis From Coordinate My Care, a Large Electronic Palliative Care Coordination System

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Background/aims: At the beginning on the COVID-19 pandemic, advance care planning (ACP) was widely encouraged and endorsed for adults with serious illness to ensure their treatment and care preferences would be honoured, including location of death, often considered a surrogate quality indicator for end-of-life care. Coordinate My Care (CMC) represents the UK's largest Electronic Palliative Care Coordination System that comprises an ACP component.

We aimed to examine the impact of ACP on place of death for people who died during the COVID-19 pandemic with a CMC record.

Methods: Retrospective cohort analysis of CMC records for people aged over 18 who died between 20/03/20 and 05/03/21 with recorded place of death. Socio-demographic, clinical and ACP-related factors associated with achieving preferred place of death (PPD) were examined using logistic regression.

Results: 11,913 records were included. 76.9% patients died in their preferred place location of death (57.7% Home, 31.4% Care Home, 7.5% Hospice, 3.3% Hospital, 0.1% Other). An increased likelihood of dying in PPD was associated with a "Not for resuscitation" (DNACPR) status (OR=1.55, 95% CI 1.23 to 1.95), a Ceiling of Treatment for Symptomatic Treatment (when compared to Full active treatment, OR=3.55, 95% CI 2.78 to 4.53), documented family discussions regarding resuscitation recommendations (OR=1.53, 95% CI 1.34 to 1.74) and 2+ non-urgent

care record views in the 30 days before death (OR=1.27, 95% CI 1.23 to 1.43). People from materially deprived areas had a decreased likelihood of dying in their PPD (OR= 0.65, 95% CI 0.54 to 0.79).

Conclusions: Modifiable elements of ACP significantly influence place of death, even when controlling for socio-economic and demographic determinants. In times of crisis, effective ACP is central to delivering high quality end-of-life care; ACP related factors must be considered in ongoing research on end-of-life outcomes.

Abstract ID: P05:13

Abstract type: Poster

Signs of Distress Among Dutch Healthcare Professionals Who Provided End-Of-Life Care During the COVID-19 Pandemic: A Longitudinal Online Survey (the CO-LIVE Study)

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Background/aims: Providing end-of-life care during the COVID-19 pandemic often involved high workload under unusual circumstances.

Aim: To describe the well-being of healthcare professionals who provided end-of-life care in the first year of the COVID-19 pandemic.

Methods: A longitudinal online survey filled in multiple times by the same 169 healthcare professionals from different professions (57% nurses, 12% physicians, 31% other) and settings (26% hospital, 15% nursing home, 22% hospice, 18% home, 19% other), who provided end-of-life care during the COVID-19 pandemic. They responded to five statements about their well-being in three different time periods: during the first wave (Mar 2020 – May 2020), second wave (Sept 2020 – Nov 2020) and a third period (Dec 2020 – Apr 2021) of the COVID-19 pandemic. Differences between these time periods were assessed using confidence intervals.

Results: During the first wave, second wave and third period: 64%, 36% and 39% of respondents reported that they were more stressed than usual. 50%, 31% and 35% stated that their work was emotionally demanding. 37%, 23% and 30% stated that their work was physically demanding. 47%, 38% and 42% stated that they felt exhausted regularly. 47%, 26% and 29% stated that they needed more emotional support than usual.

For every statement, except the one on exhaustion, the decrease in percentage of respondents agreeing with the statement between the first and second wave was significant. The percentages were slightly higher again in the third period, although not significant.

Conclusions: During the first year of the COVID-19 pandemic, a substantial part of healthcare professionals showed signs of distress. That means that the well-being of healthcare professionals is at stake. It is important to study how this further develops and what healthcare professionals' needs are to endure and recover from these challenging times.

Funding: ZonMw

Abstract ID: P05:15

Abstract type: Poster

An Evaluation of End of Life Care Experiences in Care Homes in the UK During the Pandemic

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Background/aims: Care homes in Europe have been profoundly impacted by the COVID-19 pandemic with increased resident mortality. They needed to respond to shifting government guidelines for infection control procedures and restrictions in visiting. This all occurred under the scrutiny of the media.

Aim: to evaluate end of life care experiences in care homes in the UK.

Methods: A mixed method approach. We used a database of about 6000 care home residents where we could track when they interacted with health care services including community nursing input, admission to hospital (and A&E) and clinic appointments. We also conducted interviews (n=24) with care home staff, residents and families from 8 care homes which were analysed using framework analysis.

Results: A large spike in deaths occurred in April/May 2020. This coincided with only about a quarter of outpatient appointments taking place. Inpatient admissions dropped by half and A&E attendance by a quarter. Community nursing input to care homes reduced by a third. Interviews suggested that staff were inundated with COVID-19 information via email but felt 'abandoned' with few nursing services operating in person. At the beginning of the pandemic some community nursing staff helped produce emergency care plans, usually over the phone, but some care homes interpreted this to mean residents were going to be 'left to die'. Care home staff felt guilt about deaths related to COVID-19 and this took a toll on their emotional well-being. This was exacerbated by needing to 'police' family visiting with residents who were actively dying.

Conclusions: Care home residents experienced a dramatic reduction in services outside of the care home coupled with a large increase in deaths. Many staff wanted greater input from external services especially community nursing teams to support them.

Abstract ID: P05:16

Abstract type: Poster

Learning From Experience: Running the EMBED-Care Cohort Study With People With Dementia and Their Carers During the COVID-19 Pandemic

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Background/aims: The Empowering Better End of Life Care (EMBED-Care) Programme aims to deliver a step-change in caring for people living with dementia towards end of life. A key workstream is a large cohort study collecting data not available elsewhere. This aims to provide an in-depth understanding and new insights into the palliative care needs of people with dementia in their last 1-2 years of life and of family carers. Here, we discuss our recruitment and retention to better understand the cohort study experience during COVID-19.

Methods: This longitudinal mixed method cohort intends to recruit 294 people living with dementia and family carers via acute hospitals in England. After baseline data collection occurs every two months for up to twelve months.

Results: During the first nine months of recruitment, participating hospitals consented one-third to one-half of those eligible to participate. To date, of those consented 52% completed baseline, 17% have completed the first follow up and 7% the third follow-up. We consider the practical and methodological challenges encountered in opening, recruiting, running and retaining participants in a large cohort study

during COVID-19. Then we reflect on our agile approach to adapt and adjust our practices as the pandemic continues and new challenges arise. We outline our attempts to ensure inclusive research practices and the practical issues in moving from face to face to remote data collection.

Conclusions: Adapting the study, which was designed pre-COVID-19, enabled the EMBED-Care cohort study to open. We reflect on our decisions and consider whether an earlier radical re-think rather than an agile approach in the context of COVID-19 restrictions may have reaped greater success. We conclude by looking ahead as to how these experiences may influence post-pandemic research practices when working with vulnerable populations.

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Abstract ID: P05:17

Abstract type: Poster

Maintaining Quality of Palliative Care in a Global Pandemic: Experiences of Health Care Professionals From 14 Countries During the COVID-19 Pandemic (the CO-LIVE Study)

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Background/aims: During the COVID-19 pandemic, measures imposed by governments and healthcare institutions to limit spreading of the disease may have negatively impacted the quality of care for dying patients. Our aim was to provide insight into similarities and differences between countries in the experiences of healthcare workers caring for patients in their last days of life during the COVID-19 pandemic.

Methods: An open online survey study, consisting of purposively designed measures of perceived quality of care for dying patients, was conducted among healthcare workers from April 2020 to June 2021 in Belgium, Czech Republic, Norway, Slovenia, the Netherlands, United Kingdom, Argentina, Brazil, Chile, Colombia, El Salvador, Uruguay, Indonesia and Japan. Descriptive statistics were calculated.

Results: A total of 3112 healthcare workers from 14 countries completed the questionnaire. The number of respondents per country ranged from 44 respondents in El Salvador, to 764 respondents in the Netherlands. The percentage of respondents who indicated that treatment and care for dying patients had been limited due to the pandemic ranged from 13% in Norway to 88% in Slovenia. Nevertheless, the majority of health care professionals considered the quality of medical care sufficient to meet the patient's needs, with percentages ranging from 73% in the Czech Republic to 99% in Colombia. Nursing care was also considered sufficient by the majority of health care professionals, with percentages ranging from 59% in Argentina to 96% in Chile.

Conclusions: Preliminary results show important differences between countries in the impact of the COVID-19 pandemic and related measures on end-of-life care. Although in all countries the majority of healthcare workers reported sufficient quality of medical and nursing care, there were large differences in perceived limitations in treatment and care due to the pandemic.

Funding: ZonMw.

Abstract ID: P05:18

Abstract type: Poster

The Grief and Support Needs of Children and Young People Bereaved During the COVID-19 Pandemic: Parental Views From a UK National Survey

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Background/aims: During the COVID-19 pandemic, many children and young people have experienced the death of close family members, whilst also facing unprecedented disruption to their lives. This study aimed to investigate the bereavement experiences and support needs from the perspective of their parents or guardians.

Methods: We analysed cross-sectional free-text data from a survey of adults bereaved in the UK during the pandemic. Participants were recruited via media, social media, national associations and community/charitable organisations. Thematic analysis was conducted on parent/guardian responses to a question on the bereavement experiences and support needs of their children.

Results: Free-text responses from 106 participants were included. Three main themes were identified: the pandemic-related challenges and struggles experienced by children and young people; family support and coping; and support from schools and services. Pandemic specific challenges include the impacts of being separated from the relative prior to their death, isolation from peers and other family members and disruption to daily routines and wider support networks. Examples were given of effective family coping and communication, but also difficulties relating to parental grief and children's existing mental health problems. The important role of schools and bereavement organisations in providing specialist support was demonstrated, but there was evidence of unmet need and lack of access to specialist grief or mental health support.

Conclusions: Children and young people have faced additional strains and challenges associated with pandemic bereavement. We recommend initiatives that facilitate open and supportive communication within family and school settings, adequate resourcing of school and community-based specialist services and increased information and signposting to the support that is available.

Abstract ID: P05:19

Abstract type: Poster

Grief After the First Wave of the Corona Pandemic: An Online Survey Among Dutch Bereaved Relatives of Patients Who Died With and Without COVID-19 (the CO-LIVE Study)

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Background/aims: The circumstances under which patients died during the first wave of the COVID-19 pandemic, such as visiting restrictions, can affect the grieving process of bereaved relatives. The aim of this study was to examine how characteristics of bereaved relatives, their

evaluation of the dying process, and being allowed to be with the patient in the last days of life are related to their grieving process.

Methods: We conducted an open observational online survey (Nov 2020-Apr 2021) among 258 bereaved relatives to study their experience of end-of-life care for a loved one who had died during the first wave (Mar 2020-Jun 2020) of the COVID-19 pandemic. Grief was measured with the Hogan despair subscale (scores between 13 and 65), with higher scores indicating more despair. Data were analysed using descriptive statistics and multivariate analyses.

Results: Most respondents were female (82%) and were children (63%) or partners (22%) of the deceased patients. The overall mean despair score was 24.6. Partners had a significantly higher mean despair score than children (33.6 vs 22.9). Terms which relatives most often selected to describe the dying process of the patient were: sad (63%), quiet (43%), painful (30%), shocking (27%) and degrading (26%). Relatives who described the dying process in more negative terms had worse mean despair scores than those who used more positive terms. Sixty percent of the relatives had not been allowed to be with the patient at the time of dying. They had higher mean despair scores (25.1) than relatives who had been allowed to be present (23.8).

Conclusions: The findings indicate that the circumstances in which patients died are related to the extent of relatives' grief. These findings underline the importance of striving for a good death in the physical presence of relatives during a pandemic. Supporting relatives is important to prevent complex grief, recognising the vulnerability of especially bereaved partners.

Abstract ID: P05:20

Abstract type: Poster

Visiting Policies in Specialist In-Patient Palliative Care Services During COVID-19 Pandemic Across Central and Eastern Europe - Quantitative and Qualitative Study

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Background/aims: Since the COVID-19 pandemic, visiting policies in various healthcare settings across the world have been changed. Patients' relatives and friends visits have been stopped or significantly limited. New conditions and legal constraints for family visits had to be implemented also at in-patient palliative care services despite the fact that accompanying dying person is crucial for the quality of the end of life.

The aim of the study was to identify and review the visiting policies at in-patient specialist palliative care settings across Central and Eastern Europe.

Methods: The study was conducted one year after the COVID-19 pandemic outbreak from May to October 2021. Information about visiting policies, published at official websites of the in-patient specialised palliative care settings from Central and Eastern European countries, were identified and categorised. The websites with the lack of any information about visiting policy during COVID-19 pandemic were excluded. Qualitative and quantitative analysis of the obtained data was conducted by using content analysis techniques and descriptive analysis.

Results: Data from 55 in-patient palliative care settings from 8 countries were collected (Bulgaria, Czech Republic, Estonia, Lithuania, Poland, Romania, Slovakia and Ukraine). In 43.6% of the organisations visits were stopped and 56.4% settings published information about the special requirements on visiting arrangements. In 32.7% of all examined units upfront approval from physician or the head of ward for visiting a patient was required, and 29.1% published the information about personal protective equipment. 32.7% of organizations recommend telephone contact with the patient, and 12.7% provided video calls.

Conclusions: Web information regarding visiting patients at in-patient palliative care settings is limited. There is a need to establish detailed requirements for the visits with better access to the website for the visitors, in case of global disease outbreak.

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Abstract ID: P05:21

Abstract type: Poster

Understanding Future Planning for Volunteering After the COVID-19 Pandemic. A Multi-National EAPC Survey

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Background/aims: Previous research on hospice and palliative care volunteering early in the COVID-19 pandemic suggested a significant decline in volunteering activity, impacting on the range, safety and effectiveness of services offered.

Aim: To explore future organisational plans for volunteer roles and deployment in hospice and specialist palliative care services in light of the ongoing response to COVID-19.

Methods: Multi-national cross-sectional survey of hospices and providers of specialist palliative care services, using a convenience sample. A 68-item online questionnaire, aimed at people responsible for volunteer deployment, was disseminated via social media, palliative care networks and key collaborators from May to July 2021. Free text questions focussed on future plans for volunteering. Free text responses were analysed using content analysis techniques.

Results: 64% (n=195) of organisations maintained contact with non-active volunteers. Many services intended to return to pre-pandemic volunteering activities. 14% (n=43) of organisations reported planning a phased re-introduction of volunteers, additional training, use of risk assessments and safe working protocols related to infection control. Others intended to be more flexible, continuing face to face roles whilst increasing virtual volunteering activities. Some planned to use volunteers more effectively, ensuring that roles matched organisational needs. Increased community volunteering was also highlighted. Others were confident that volunteers would return and undertook no planning.

Conclusions: The approach to planning for the future of volunteering is not consistent. It was assumed that volunteers will return to roles as before. Urgent consideration must be given to engaging with volunteers to ascertain how many will return, identifying gaps, developing safe protocols for return, assessing future support and training requirements for changed environments and new ways of working.

Abstract ID: P05:22

Abstract type: Poster

Improving Palliative Care Access for People From Ethnic Minorities During COVID-19 Pandemic: Findings From a Service Evaluation

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Background/aims: A specialist palliative care service evaluation in an acute hospital during the first wave of COVID-19 showed that those from ethnic minority backgrounds, especially women, were referred later. Improvements in treatments, and operational and system-level changes to the palliative care service which were introduced to address this disparity, may have improved access for those from ethnic minorities. *Aim:* To assess the effectiveness of operational and system-level changes to the hospital specialist palliative care service, by examining care patterns and trends for those with COVID-19.

Methods: Retrospective service evaluation comparing patients referred to an acute hospital palliative care service with confirmed COVID-19 infection either at the peak of the first (Mar-Apr 2020, W1) or second (Dec 2020-Feb 2021, W2) wave of the pandemic. Demographic, clinical characteristics, and outcomes data were collected and compared using statistical tests; generalised linear mixed models for modelling of elapsed time from admission to referral; and survival analysis for each wave.

Results: Data from 165 patients (W1 = 60, W2 =105) were included. Overall, patients in W1 were referred earlier to palliative care than in W2, particularly in the first 8 days from admission. Receiving dexamethasone, anticoagulants and absence of dementia, hypertension, and fever were associated with longer time to referral. The delay in referral from W1 of Black and Asian patients of 2-4 days, accounting for 22%-44% of the overall time from admission to death, was no longer observable in W2. The Australian-modified Karnofsky Performance Status (HR < 0.92, upper CI < 0.97) and phase of illness (HR > 3, lower CI >2) were good predictors of survival in both waves.

Conclusions: The delayed referrals for ethnic minorities were not seen in W2. Actions to integrate palliative care within organisational COVID-19 planning, engaging with minority ethnic groups, and educating the workforce on culturally sensitive approaches to care may have had a positive impact on access to palliative care.

Abstract ID: P05:23

Abstract type: Poster

The Development and Evaluation of Online Home Palliative Training During COVID-19 Pandemic in South Africa

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Background/aims: COVID-19 has compounded the lack of access to palliative care described in the Lancet Commission. COVID-19 patients and their families report distressing multidimensional symptoms and concerns. South Africa faced a high burden of COVID-19, and due to restrictions in facility access there was need for upskilling of healthcare professionals to deliver home palliative care irrespective of diagnosis.

Aim: To develop and evaluate online training of palliative home care.

Methods: We developed: 1) guidelines for health care professionals and family caregivers using a multidisciplinary team of stakeholders from across South Africa, 2) online training covering palliative care management of COVID-19 and non-COVID-19 patients at home, completed over 4 weeks and 3) training evaluation using an online questionnaire and qualitative interviews.

Results: Between March and May 2021, n=950 participants were registered for online asynchronous training. Of these, n=247 engaged with the training materials, n=141 completed assessments, receiving a certificate of completion with CPD accreditation for professionals. Survey data were collected from 53 participants: n=27 health professionals (n=13 nurses, n=5 doctors, n=3 social workers, n=3 counsellors; n=2 rehabilitation sciences, and n=1 emergency medicine), and n=26 non-professionals.

Thirty-one (58.9%) had no previous palliative care training; n=22 (41.5%) had no previous experience in providing palliative care. Implementation outcome measurement: agreement with being able to apply the training clinically was 4/5 for 27 (51.0%) and 5/5 for 19 (35.8%) on a 5-point Likert scale; and 34 (64.2%) completely agreed (5/5) to welcoming the opportunity to develop palliative care knowledge and skills.

Conclusions: The interest shown in the guidelines and training reflect an awareness of the importance of these skills, and the delivery method offers enormous potential to build skills and knowledge in an accessible format.

Funding: NIHR and UK Aid

Abstract ID: P05:24

Abstract type: Poster

Mapping Interventions for Family Members Grieving the Loss of a Relative Who Died From COVID-19: A Scoping Review

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Background/aims: The COVID-19 pandemic has caused considerable disruptions to daily social routines and to the lived and subjective experience of grief and bereavement. We performed a scoping review of the scientific literature to understand the extent to which psychosocial and psychotherapeutic support for family members grieving the loss of a relative who died from COVID-19 are offered in health and social care facilities and community settings.

Methods: The scoping review used Arksey and O'Malley's framework and the principles of the Joanna Briggs Institute. A systematic literature search is carried out to identify relevant evidence through the following research databases: PubMed, CINAHL Complete, PsycINFO, Scopus and Web of Science. Relevant grey literature, preprints and research protocols registries were retrievable through supplemental online resources. The database search is limited to studies from February 2020 [first death by COVID-19] to the study's start date.

Results: From the 40 identified articles, 5 were included in the analysis. Efforts to aid the bereaved have increasingly focused on the physical and psychological morbidity and the spiritual suffering and social isolation associated with bereavement. Some psychosocial strategies are presented and include support groups, counselling, self-care or self-management, educational programs, workshops, telehealth, and online support. In addition, psychotherapeutic interventions are mostly based on cognitive-behavioural components with the bereaved because they reduce the future probability of psychological or medical problems.

Conclusions: Expressions of condolence, affection and spirituality tend to be important resources for many families, contributing to activating coping mechanisms and fostering adjustment and resilience in the face of loss. Healthcare professionals should be prepared for post bereavement support favouring the necessary referrals when there are risk factors for prolonged grief.

Abstract ID: P05:26

Abstract type: Poster

Did the COVID-19 Pandemic Affect Referral and Admittance to Specialized Palliative Care in Denmark?

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Background/aims: In 2020, the COVID-19 pandemic led to restrictions in Denmark (and elsewhere), which reduced contact between patients potentially in need of specialized palliative care and referring physicians. This may have impacted referral to specialized palliative care. The capacity of specialized palliative care to admit patients may also have been affected. The study aims were to investigate whether there was a change from 2019 to 2020 in 1) the number of referrals to specialized palliative care, 2) the proportion of eligible referred patients admitted and 3) the waiting time.

Methods: Data was obtained from the Danish Palliative Care Database for adult patients referred to specialized palliative care with death in 2019-2020. We computed 1) the number of referrals to specialized palliative care, 2) the proportion admitted to specialized palliative care among those referred who fulfilled the criteria for admittance, 3) the proportion of those admitted to of specialized palliative care, who were admitted within ten days from referral.

Results: From 2019 to 2020, referrals to specialized palliative care decreased with 5% (from 17,362 in 2019 to 16,458 in 2020), whereas the proportion of patients admitted increased from 81% to 82%. The proportion admitted within ten days from referral also increased from 73% to 76%.

Conclusions: Referral (i.e., detection of patients in need of specialized palliative care) to specialized palliative care was reduced more than the capacity to admit patients, leading to a slight increase in the proportion of patients admitted to specialized palliative care and a reduction in waiting time.

Abstract ID: P05:27

Abstract type: Poster

Understanding the Palliative Care Support Needs of Hospitalised Patients With COVID-19; Are Subcutaneous Infusions Associated With Improved Symptoms?

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Background/aims: Recent systematic review of symptom management for adult COVID-19 patients approaching end of life (Heath, 2021), identified 7 studies (493 patients); only 4 reported if symptom management was effective. Over 2/3rds patients needed subcutaneous infusion for symptom control. We aimed to identify if subcutaneous infusions for adult COVID-19 patients approaching end of life was associated with improved symptoms.

Methods: Two UK acute hospitals. Survey of all adult patients with COVID-19 seen 1st April 2020 to 31st March 2021 by the hospital advisory palliative care teams. Symptom data was prospectively collected. Approved by the clinical audit committee.

Results: 252 COVID-19 patients; mean age 78.9 yrs (range 42-98), 56% female; mean duration of care 3.2 days (median 3, range 1-35). 200 (79.4%) died in hospital; 25 (9.9%) were discharged and remained in hospital; 12 (4.8%) were discharged to inpatient hospice care; 15 (5.9%) to own/care home. 147 (58.3%) patients required continuous subcutaneous infusion for symptoms; of these, 36 (24.5%) had pain when first seen; 82 (55.8%) had breathlessness; 92 (62.6%) had agitation/distress. Of those who had or developed pain (n=43), 26 (60.5%) improved with morphine or oxycodone infusion; 17 (39.5%) worse or unknown. Of those who had or developed breathlessness (n=82), 50 (61.0%) improved with morphine or oxycodone infusion; 32 (39.0%) worse or unknown. Of those who had or developed agitation/distress (n=92), 50 (54.3%) improved with midazolam, haloperidol, or levomepromazine infusion; 42 (45.6%) worse or unknown. Mean doses were: morphine 14.2mg/day (range 5-60mg); oxycodone 21.4mg/day (range 5-80mg); midazolam 15.4mg/day (range 5-80mg); haloperidol 2.4mg (range 1-5mg); levomepromazine 23.75mg (range 6.25-50mg).

Conclusions: Despite deteriorating illness, over half of all patients managed with often low doses of common medicines administered by subcutaneous infusion had improvement of their symptoms.

Abstract ID: P05:28

Abstract type: Poster

Emotional Impact of COVID-19 on Palliative Care Healthcare Professionals

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Background/aims: Palliative care professionals (PCP) work in an environment of great emotional impact where patients and caregivers present high levels of emotional distress and suffering. Working in these units frequently involves high levels of emotional distress. The emergence of the COVID-19 pandemic has intensified this emotional distress. The aim of this work was to analyze the levels of emotional distress of palliative care health professionals during the second wave of the pandemic in Spain.

Methods: A descriptive cross-sectional study of palliative care health professionals who responded to an online survey during the second COVID-19 pandemic in Spain (July 2020).

95 palliative care professionals (58 women and 37 men) with a mean age of 45.72 ± 11.71 years responded to an online survey voluntarily, after giving informed consent. In addition to sociodemographic variables, anxiety, depression, emotional distress, post-traumatic stress, and questions related to the COVID-19 situation and the institution were analyzed. The study was approved by the Ethics Committee of the Autonomous University of Barcelona.

Results: 53.7% of the health professionals reported anxiety, 46.7% depression, 54.5% emotional distress, and 28% post-traumatic stress disorder (PTSD). A 26.5% of the professionals think that they require psychological help. 32.8% believe that they feel recognized by their institution, and 28.7% feel cared for by their institution. We observe that the professionals who feel recognized by their institutions experience less emotional distress ($p < 0.01$) and believe they need less psychological support ($p < 0.05$) than those who do not perceive it.

Conclusions: A high emotional impact generated by the COVID-19 pandemic is observed in PC professionals. It would be necessary to provide psychological resources related to emotional regulation and coping strategies to deal with this situation of high emotional impact generated by the pandemic and promote their well-being and facilitate coping of future pandemics.

New Technologies and Digital Health

Abstract ID: P06:01

Abstract type: Poster

Concept of a Simple Reaction Test for eHealth-Based Opioid Response Assessment in Palliative Care

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Background/aims: Opioids are often used to reduce symptom burden in palliative care. To allow for maximum therapeutic effect and minimal adverse effects (AE), AE have to be monitored. One side effect of opioids is a reduction in cognitive function. Various aspects of cognitive function can be assessed by tests and questionnaires, such as the confusion assessment method (CAM) or Nine Hole Peg Test. All tests are time-consuming and need to be conducted by health care professionals. We aim to develop a simple smartphone-based reaction test as eHealth application in palliative care. Here, we present initial results of healthy participants which serve as baseline for future work.

Methods: We implemented a simple reaction test as smartphone application: Users are tasked with pressing the screen when the color of the display changes. The reaction time (RT) between the color change and the press of the display is recorded. A field study with 15 healthy young participants was conducted. One RT test consists of four color changes. Each participant performed ten tests. Additional metrics were assessed by a questionnaire (sex, fatigue, work activity, previous experience with the application).

Results: Average reaction time was 391.81 ± 49.26 ms across all individuals. Fatigue did not have an impact on reaction time. Average intraindividual deviation was significantly different between first time (35.91 ± 10.53 ms) and experienced (18.75 ± 3.45 ms) users.

Conclusions: We developed a fast, simple and digital reaction test. The reaction test average stayed constant for all groups. Intraindividual reaction time deviation may serve as a boundary to determine an unusual decrease in cognitive processing time (CPT). We aim to assess the influence of factors like medication on a more heterogeneous as well as patient population in the future. This allows us to determine whether our test pipeline is able to reliably detect CPT decrease.

Abstract ID: P06:02

Abstract type: Poster

Patient Satisfaction with Telehealth Consultations in a Community Palliative Care Service: A Mixed Methods Study

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Background/aims: Community Palliative Care (CPC) in Ireland has traditionally been delivered face to face in the home or the outpatient clinic setting. The COVID-19 pandemic necessitated the introduction of Video Consultation (VC) as a modality of CPC service provision. Evidence supports the feasibility of VC in CPC. There is a paucity of evidence regarding patient satisfaction with key components of the palliative care consultation when delivered virtually. To incorporate VC into routine practice, evaluation of the service user experience is essential.

Methods: Mixed quantitative and qualitative study. The formulated telephone questionnaire evaluated satisfaction with VC in three domains; Use of Technology, Communication using Video Technology and Components of the Palliative Care Consultation. Results were analysed descriptively with thematic analysis of free text additional information.

Results: All patients (n=19) were satisfied or very satisfied with VC. The majority of patients (79%) had not used VC as a modality for interactions with healthcare professionals previously. All patients felt able to communicate what they wanted to say. The majority felt comfortable asking questions (84%) and most (78%) were not concerned that they could not be physically examined. Patients were satisfied with discussing physical symptoms (84%) and medications (100%). Areas that were not discussed or had less favourable feedback included spirituality and faith and discussing future care. Themes identified included: Flexibility offered by VC, identification of an ongoing role for VC and overall preference for face to face interaction.

Conclusions: Patients were satisfied with VC as a mechanism of CPC provision overall. Levels of satisfaction varied across key components of the consultation demonstrating the strengths and limitations of this

modality at present. This provides clinicians with valuable information to guide future research and service development.

Abstract ID: P06:03

Abstract type: Poster

Development of 'Use-Cases' for a Digital Palliative Care Bereavement Service

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Background/aims: Grief is a natural process, in which many people will cope with help from their friends and family. However, many people will need professional help. Good bereavement care is important to ensure that people get the support they need when they are grieving. Digital tools can potentially provide support for bereaved people; however, this has not been extensively studied. In computer systems design, 'use-cases' describe individual event steps a user needs to navigate to complete an action or goal on a digital system. Well-designed use-cases can improve the efficacy and effectiveness of the developed system. Use-cases for digital bereavement support have not been established; therefore, there is potential that their use could facilitate development of digital bereavement services. We aim to develop 'use-cases' to describe the 'event steps' needed to design a digital service to provide three tiers of bereavement support, based on recommendations of the UK National Institute for Health and Clinical Excellence (NICE).

Methods: We will review national UK relevant policy on palliative care bereavement services, and we will conduct semi-structured interviews with key stakeholders, to inform the development of 'use-cases'.

Results: In the short term, we use the outcomes of this work to explore how 'use-cases' can inform best use of existing technological systems. In the medium to long term, we will develop a research study where we will use these 'use-cases' to develop and test a digital bereavement service, to determine the effectiveness in providing support for bereaved persons.

Conclusions: We anticipate that this study will result in purposeful development of digital resources that take advantages of emerging technologies to deliver bereavement support. Using our approach, future studies can utilise the 'use case' method to improve the evidence base for digital health studies in palliative care. This will improve capacity for future palliative care research.

Abstract ID: P06:04

Abstract type: Poster

The DIGNITAL Study

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Background: Dignity Therapy (DT) is a validated psycho-therapeutic intervention designed to influence a sense of meaning and purpose for individuals and their families. DT is well received by patients and family

members, with research identifying improvements in measures of well-being and overall quality of life. Few studies include young adults (YA) with life-limiting conditions (LLC). A focused review and consultation work suggests a need to develop and evaluate a digital DT based intervention for YA/LLC.

Aims: 1) Adapt the current Dignity Therapy Question Protocol (DTQP) for YA/LLC and explore user perspectives on potential effectiveness of DIGNITAL. 2) Develop DIGNITAL, a digital DT based intervention to support wider accessibility and acceptability amongst YA/LLC. 3) Evaluate the revised DTQP and DIGNITAL for YA/LLC.

All participants are recruited via children and young adult hospice facilities in England.

Methods: A three-phased qualitative design:

1) YA/LLC interviews (n=18) and 3 health care professionals (HCP) focus groups (n=15) to inform adaption of the DTQP and the content of DIGNITAL.

2) Develop and amend DIGNITAL using themes from phase 1 and 3.

3) Evaluate revised DTQP and DIGNITAL - 3 focus groups with YA/LLC (n=186), 3 focus groups with HCP (n=15) and interviews with YA/LLC new to study (n=9).

This work is supported by an expert user group of six YA/LLC. The qualitative data will be analysed using Framework Analysis.

Results: The study will develop DIGNITAL, a digital DT based intervention for YA/LLC. User perspectives will be reported via key themes of the framework analyses.

Conclusions: DIGNITAL is created with and for users. We plan to undertake a subsequent feasibility study.

This project is funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number NIHR201597). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Abstract ID: P06:05

Abstract type: Poster

A Systematic Review of Using Virtual Reality Technology in Palliative Care

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Background/aims: Virtual Reality (VR) has the potential to ease patient symptomatology but its efficacy is not known.

Aim: A systematic review on the feasibility and effectiveness of VR intervention in a palliative care setting.

Methods: Medline, Embase, AMED, PsycINFO, CINAHL, Cochrane Central Register of Controlled Trials and Web of Science were searched from inception up to March 2021. Studies that reported on the use of VR in an adult (over 18 years) palliative population were included. The ROB-2 (for RCTs) and ROBINS tools (for non-RCTs) were used to assess risk of bias. The GRADE tool assessed the quality of the evidence. The standardised mean differences were calculated from the pre- and post- data of the Edmonton Symptom Assessment System-revised (ESAS-r). A DerSimonian-Laird random effects model meta-analysis was conducted. Registered: PROSPERO (CRD42021240395, 03/03/2021)

Results: 8 studies were included, 3 were included in the meta-analysis. All studies had at least some concern for risk of bias. 225 patients used the VR technology. Patient diagnoses included cancer (3/8; 37.5%), multiple (3/8; 37.5%), advanced heart disease (1/8; 12.5%), and dementia (1/8; 12.5%). 44% (97/219) were male; the mean age ranged from 47 to

85 (years). Recruitment was feasible and retention rates ranged between 55% and 100%. Overall, participants reported a positive experience with using VR and were happy to repeat the experience. Discomfort and technical issues were recorded in 4/7 studies (57%). The meta-analysis showed limited evidence for VR across the domains of the ESAS-r. The quality of the evidence was rated as low to very low.

Conclusions: VR in palliative care is feasible and has varying acceptability. Limited sample sizes and low-quality studies mean that the efficacy of VR is difficult to draw definitive conclusions on. Existing studies provide valuable insights and guidance into how to set up VR in clinical practice settings and the challenges to expect.

Abstract ID: P06:06

Abstract type: Poster

How Can Technology Be Used to Support Communication in Palliative Care Beyond the COVID-19 Pandemic?

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Background/aims: Developments in digital health has the potential to transform the delivery of health and social care by creating new opportunities for healthcare professionals to deliver care. For example, during the COVID-19 pandemic, palliative care services have used digital health to support communication with staff, patients and caregivers. However, there is limited data on staff perspectives of using digital health for communication during the pandemic, which limits our ability to learn how digital health tools can be used beyond the pandemic to support palliative care communication in clinical practice.

Methods: We developed an electronic questionnaire (requiring multiple choice and free text responses), for UK based palliative care healthcare professionals, to identify how they have used digital health to support communication in clinical care during the COVID-19 pandemic. We circulated the questionnaire through professional networks and through social media. The questions involved: (1) communication within the multidisciplinary team (MDT), (2) education and (3) to support communication with patients and carers. We used thematic analysis to analyse free text responses and identify themes.

Results: Two hundred and thirty-four palliative care professionals participated. Most (n= 227, 97%) had increased their use of digital health, to support communication, since the pandemic started. We identified benefits and challenges for digital health communication, which we summarised into themes to identify facilitators and barriers for future use of this technology in clinical practice.

Conclusions: Since the pandemic, palliative care professionals described increased use of digital health to support communication. We have identified facilitators and barriers for future practice. We believe that should work should identify support to enable organisations to implement the models of care needed to improve access and quality of palliative care services.

Abstract ID: P06:07

Abstract type: Poster

Launching a Virtual Bereavement Café Developed and Run by Staff, for Staff, in 2 National English Public Health Organisations During the COVID-19 Pandemic

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Background/aims: The COVID-19 pandemic has adversely impacted bereavement experience by restrictions: visiting the dying, funerals, family meetings, access to bereavement services. Public health work on the pandemic and other essential functions has been unrelenting. Enforced home working enhanced isolation. Many colleagues were experiencing difficult bereavements with little access to support.

Methods: A grassroots group of bereaved staff or with expertise in bereavement established an infrastructure to run Virtual Bereavement Cafés by staff for staff across the 2 national public health organisations. The Chief Executive gave support. MS Teams (video teleconferencing, chat and signposting to resources) was used to provide a safe, mutually supportive space for staff to meet virtually. Cafés were 45 minutes every fortnight, facilitated with mental health first aiders present. Ground rules emphasised respect, confidentiality, the validity of all types of grief and all deaths whether pre or during the pandemic. Chat and comforting emojis were used to offer support. Post café support was provided via email and/or a call.

Results: 10 cafés were held May to September 2021. Attendance 14 to 34 with new staff at each. Topics emerged from shared experiences, including anticipatory, complicated, cumulative and disenfranchised grief. Thematic synthesis of discussions and chat identified isolation, distress from limited funeral attendance, presence at death, and lack of workplace understanding.

Conclusions: Virtual Bereavement Cafés have provided key emotional support during the pandemic. Improvements identified for implementation include: technical enhancements with use of interactive technologies to dynamically identify topics for discussion; increased facilitator capacity to enable break out groups and more monitoring; debrief sessions for facilitators to support their wellbeing; themed sessions publicised in advance, including practical topics; increased signposting to resources. The Cafés will now implement the learning.

Abstract ID: P06:08

Abstract type: Poster

A Comparison of Palliative Care Outcomes Assessment Completion; Inpatients and Homecare Patients

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Background/aims: To compare compliance in PCOC assessment completion between homecare patients and inpatients.

Methods: PCOC data was retrospectively audited of inpatients (n=10) in a specialist palliative care unit and homecare patients (n=10) using the validated *Response to PCOC Assessments* audit tool. Patient notes closed through discharge or death were included. Results were compared.

Results: PCOC assessment completion was significantly higher for homecare patients. All five PCOC assessments were completed on initial assessment for homecare patients with a 50% completion rate for inpatients. 87% of PCOC assessments were completed at contact for homecare patients with a 5% daily completion rate for inpatients. Date ready for care was recorded for all homecare patients and 60% of inpatients. *Episode start date* was recorded for all homecare patients and 40% of inpatients.

Conclusions: The results demonstrate a lower PCOC assessment completion rate in the paper-based inpatient setting compared to the electronic-based homecare setting. The higher compliance rate in homecare may be accounted for in part by the automated electronic system, mandating the filling of all fields before proceeding. The potential development of an electronic PCOC system for inpatients is an area for research and development. No funding.

Abstract ID: P06:09

Abstract type: Poster

Clinical Impressions of Electronic Patient-Reported Outcomes in Paediatric Oncology Based on Single Case Reports in the MyPal Project

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Background/aims: The necessity and potential benefits of using electronic patient-reported outcomes (ePROs) in paediatric oncology and palliative care are well documented. The nature and severity of these patients' conditions pose great demands for care and communication. ePROs can help to detect unrecognised symptoms and unmet needs of this vulnerable patient group, while also involving them more in the treatment process. The feasibility of using a novel eHealth platform to encourage active patient engagement in paediatric oncology and palliative care is assessed within the scope of a multi-site clinical observational study.

Its objective is to empirically examine the clinical and methodological usage of the ePRO-based platform in clinical practice and research. Our work aims to provide first-hand experience of how to deploy and exploit such a platform for optimised doctor-patient communication and hence for improved medical and psychosocial care in paediatric oncology and palliative care.

Methods: User needs, functionalities and ethical issues were empirically examined in 4 pre-study focus groups with 21 participants. The platform comprises two mobile applications: the gamified MyPal-Child and MyPal-Carer App which are tested during a 6-month period. The apps provide self-report symptoms scales and diary entries. Reported data are visualised graphically for the medical staff via a web interface.

Results: The focus groups indicated a need for and interest in alternative communication when dealing with children with cancer. Qualitative observations of single cases show that ePROs can be useful for diagnostic purposes and other therapeutic interventions.

Conclusions: Preliminary results show that ePRO can be valuable under certain conditions. Final discussions on the validity of these findings remains open until the end of study in December 2022.

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Abstract ID: P06:10

Abstract type: Poster

Patient Voices: A Feasibility Study of Electronic Patient-Reported Outcome Assessment in a Comprehensive Cancer Centre

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Background/aims: Routine assessment of Patient Reported Outcome Measures (PROMs) is an indicator of integration between oncology and palliative care (PC), yet it is seldom applied in clinical practice. Electronic PROMs assessment (ePROMs), may be helpful in overcoming some barriers.

To assess compliance, acceptability and usability of a routine ePROM assessment in clinical oncology practice.

Methods: A nurse administered ePROMs via tablet to patients in different disease type and stage. In-patients completed the Distress Thermometer once during admission, while out-patient completed the Edmonton Symptom Assessment System or the Therapy Impact Questionnaire at each visit for 2 months. Cause of non-compliance (NC), patients' interaction needs/reasons and the System Usability Scale (SUS, range 0-100) were collected.

Results: Among 441 patients screened, 309 successfully completed the ePROM at baseline (70%; 95%CI 66% to 74%). NC rate was similar for in- and out-patients (29.6% vs 30.4%), with some difference between wards/clinics (range 9% to 41%, the lowest in PC clinic); also NC reasons were different between in- and out-patients: organizational issues (2% and 19%) and patient refusal (15% and 4%). Interaction need for tablet usage was 10% and 30% respectively for in- and out-patients, while interaction need for item interpretation was similar in the two groups (13% and 18%). The nurse filled-in the ePROMs upon interview in 7% and 8% cases respectively. Average SUS scores indicate high usability in both groups (86.7 and 84.1). Average repeated measurement compliance (out-patients only) was 75%.

Conclusions: Overall, results show good patient compliance, acceptability and usability of the system with some variability among wards and tools applied. Higher compliance was recorded where systematic PROM assessment is a component of clinical practice (e.g., PC clinic).

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Telemedicine for Outpatient Palliative Care During COVID-19 Pandemics. Feasibility and Patients Experience of Care at a Comprehensive Cancer Centre

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Background/aims: With the worldwide COVID-19 pandemic outbreak, telemedicine has emerged as an important mean to reduce risks of transmission by still delivering the necessary care to patients.

Our aim was to evaluate feasibility, characteristics and satisfaction for a telemedicine service based on phone or video consultations for patients attending an outpatient palliative care clinic during COVID-19 pandemics.

Methods: A longitudinal observational study was conducted from April to December 2020. Consecutive patients were screened for video consultations feasibility. Either the patients or their caregivers were contacted via video or phone consultation recording reason of the call and intervention performed. Patients or caregivers contacted at least twice were eligible for a phone interview to evaluate their experience with the service.

Results: Among 572 screened patients, 282 (49%, 95%CI 45% to 52%) were potentially eligible for a video consultation (accepted it, had technology available, did not lack help). 112 patients had at least two contacts, and 11% of them had one or more video-calls. 56% of the calls were done with patients, 30% with caregivers and 14% with both. In most cases (63%) the patient/caregiver requested the consultation. Reasons for tele-consultation included uncontrolled symptoms (66%),

new symptoms onset (20%), therapy clarifications (37%) and update on diagnostic tests (28%). Most interventions were therapy modifications (70%) and appointments' rescheduling (51%). 49 patients and 19 caregivers were interviewed; most of them reported high satisfaction scores (range 1-5, mean 3.9 and 4.2 respectively), no communication issues, and the great majority declared they would use telemedicine also after the pandemics (83% and 84%).

Conclusions: Although feasibility is still limited for some patients, telemedicine can be an acceptable alternative to in-person visits for palliative care patients in need of limiting access to the hospital.

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Co-designing an Implementation Plan For an eHealth Intervention to Optimise Care For People With Dementia in Care Homes

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Background/aims: eHealth can improve access to healthcare for people with dementia in care homes, to optimise comprehensive assessment and decisions regarding care. Evidence for its efficacy however is insufficient to ensure its adoption in routine practice, and implementation planning is often neglected. Involvement of end-users throughout the implementation process can facilitate adoption, and is a key strategy for promoting translation of findings into practice. The aim of this study was to co-design an implementation plan for use of an eHealth intervention in care homes.

Methods: An iterative qualitative co-design method was applied through a series of six workshops. Participants included people living with dementia, family carers and practitioners with direct experience of working with dementia in a care home. The workshops focused on co-developing implementation strategies in response to factors identified to influence implementation. A deductive thematic analytic approach was taken, guided by the constructs of the Normalisation Process Theory (NPT).

Results: Implementation strategies were selected which aligned with the NPT. To target 'coherence', strategies were selected which promoted the value and benefits of the intervention. 'Cognitive participation' was targeted through strategies which aim to maximise engagement with the intervention, including identifying 'champions' and engaging care home leaders. To foster 'collective action', strategies included providing training and user prompts for clinicians. Strategies around ongoing adjustment and evaluation of the plan targeted 'reflexive monitoring'.

Conclusions: Implementing eHealth into a complex care system is a multifaceted process, involving multiple stakeholders. Collaborating with end-users increases the value, credibility and real world relevance attributable to the implementation plan. The theoretically informed strategies target mechanisms previously demonstrated to shape implementation process and outcomes, ready for user-testing in care homes.

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Knowing Perceptions of Patients/Relatives, Volunteers and Professionals About Digital Volunteering

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Background/aims: Pandemic has generated emotional/social/spiritual distress. Palliative Care (PC) Home Teams are faced with limitations, aggravating consequences of pandemic. However, support of volunteers could not be carried out due to the restrictions.

It is important offer response to this situation to implement tools/resources meet needs identified. Use of New Technologies (NT) in volunteer assistance programmes, favouring accompaniment of volunteers through digital tools can provide series of advantages help to improve efficiency.

Knowing opinions of patients, families, health care professionals (HCP) and volunteers which are involved in implementation of new service.

Methods: Qualitative methodology through in-depth interviews and focus groups to explore opinions on digital volunteering, differences with face-to-face volunteering and preference of activities. Information was assessed by discourse analysis.

Results: 5 patients/5 relatives were questioned in-depth interviews. Professionals and volunteers in focus groups.

2 focus groups of HCP where participated 14 from all areas.

5 volunteers participated focus group who had been collaborating in PC for about 5 years.

Patients were reluctant and perceive barriers to communication. However, they are aware of situation. Relatives accepted better NT. They think role of volunteer for patient, although perceive as beneficial for emotional airing and instrumental aids.

HCP generally perceived was good time to integrate NT. However, they were concerned about lack of limits of role produced by immediacy of NT.

The volunteers' perception of their role is the opposite, being aware of risks and demanding training. They were concerned about relationship through screen, losing close contact with the patient.

Conclusions: The results are valuable for programme implementation to meet everyone's expectations and needs.

It contributes to development of PC volunteering research.

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Uncovering the Daily Experiences of People Living With Advanced Cancer: The Development and Validation of an Experience Sampling Questionnaire

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Background/aims: Experience sampling methods (ESM) –successfully used daily diary methods in mental health research and practice– have unknown feasibility and clinical utility within cancer care and research. We aimed to create and validate an ESM questionnaire that can provide insights into the dynamic daily experiences of people with advanced cancer, by readministering the same questionnaire multiple times a day over several days through a handheld device.

Methods: The questionnaire covers health-related quality of life (HRQOL) in the physical, psychosocial and spiritual domains, positive and negative affect, and context items (e.g., activities, social setting). Following a pre-defined procedure based on instruments' relevance, content validity and breadth of coverage, we used van Roij et al.'s (2018) overview of traditional HRQOL questionnaires to create a pool

of items. Affect and context items were selected from an existing international ESM item repository (step 1). We used Dutch versions for all items, removed duplicates, adapted resulting items to in-the-moment assessments (e.g., "In this moment, I feel . . ."), and removed those unsuitable for this purpose (e.g., "I make each day count."; step 2). We aim to interview 8 healthcare professionals and 32 people with advanced breast or lung cancer to validate the resulting item list (step 3).

Results: The item selection procedure resulted in 96 HRQOL items from the EORTC QLQ-C30, IPOS and FACIT-Pal measures, 18 positive and negative affect, and 18 context items from existing ESM surveys (step 1), reduced to 37 HRQOL items, 17 affect items, and 18 context items in step 2. Validation interviews (step 3) will be finished by the end of 2021.

Conclusions: The feasibility and clinical utility of the developed ESM tool will be evaluated as an m-health intervention for advanced cancer patients to improve our understanding of the onset, fluctuations and temporal associations of symptoms and emotions in the context of daily life, to improve care.

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The Acceptability and Effectiveness of eHealth Interventions to Support Assessment and Decision Making for People With Dementia Living in Care Homes: A Systematic Review

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Background/aims: As dementia progresses, care needs increase, leading people to live in care homes. eHealth interventions may be used to support assessment of needs and decision making. However, little is known about the acceptability and effectiveness of these interventions for people living with dementia in care homes.

This review aims to: 1) identify the components; 2) explore the acceptability to residents/family/staff; and 3) consider the effectiveness of eHealth interventions to support assessment and decision-making for people living with dementia in care homes.

Methods: Systematic review using narrative synthesis. Four databases were searched from 2000-2021. Eligibility criteria: care home residents living with dementia, eHealth interventions, all outcomes relating to acceptability and effectiveness. Non-English language, opinion pieces, editorials and PhD theses were excluded.

Results: After de-duplication, 1359 articles were yielded from the searches, 188 were screened at full text. 26 articles were included (5 RCTs; 7 quasi-experimental; 3 cross-sectional; 2 cohort, 5 qualitative and 4 mixed methods). Interventions included: video consultations, electronic health records, multi-component interventions, personal devices, digital assessment tools and decision-making tools. Core components included: Access to external medical expertise, resident and family involvement and staff training. Acceptability centred around interventions that improved resident care and staff efficiency, such as accessing and completing records at point of care. Outcomes were heterogeneous, and evidence of effectiveness was mixed.

Conclusions: In a rapidly growing digital world, it is important that eHealth interventions used for people living with dementia in care homes are deemed to be beneficial to resident's care and that staff expertise is recognised and valued within them.

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