

# 7th Public Health Palliative Care International Conference. Democratizing caring, dying and grieving: participation, action, understanding and evaluation

20-23 SEPTEMBER 2022 - BRUGES, BELGIUM

[www.PHPCI2022.com](http://www.PHPCI2022.com)

*Welcome from the PHPCI President*

Dear colleagues

As President of Public Health Palliative Care International, it is a pleasure to welcome you to the 7<sup>th</sup> Public Health Palliative Care International Conference in Bruges, Belgium.

Three years ago in the Blue Mountains, Australia, we could never have imagined what was ahead of us. Many of you know that the magnificent natural environment around that venue was decimated by fire just a few months later when bushfires raged through many parts of Australia. And then, of course, the COVID-19 pandemic began and we have all experienced its impact in different ways. We pay tribute to the dedicated and resilient communities and healthcare service personnel who have supported others during this time, and honour all those whose lives have been lost, and those who grieve them.

Like many other Associations, PHPCI has not been immune from the pandemic's impact. Our practice has been to provide a conference every two years, but it was not possible to do this in 2021. In consultation with the PHPCI Council, the Conference Organising Committee committed to deliver the conference after a year's postponement. I express my gratitude to Prof. Luc Deliens and Prof. Joachim Cohen and their team for this assurance to continue with their preparations to meet face-to-face once more.

The scientific and cultural programs have been carefully prepared by the committees and this gathering promises to showcase the many elements of public health palliative care from all over the world. Future-focussed thinking and innovation will stimulate our vision for the future. The cultural engagement with the City of Bruges provides an opportunity to see how the civic, social and healthcare worlds can partner to support whole communities.

It is also an opportunity to see how Public Health Palliative Care International plays a role in the promotion of public health approaches to the issues of dying, death, grieving and caregiving. Please consider joining us as members (go to [www.phpci.org](http://www.phpci.org)) and contribute to this work.

On behalf of the Council of PHPCI, I wish us all a stimulating and engaging 7<sup>th</sup> International Conference.



Dr John Rosenberg

President, Public Health Palliative Care International

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*Welcome from the joint chairs of the Scientific Committee*

It is our great pleasure to welcome you all to the 7th World Congress of Public Health Palliative Care International, PHPCI 2022, in Bruges. This congress brings together the state of the art in the science and practice of public health and palliative care. We welcome you also to the beautiful city of Bruges in Belgium and to Compassionate Bruges.

There is increasing recognition that the challenges around serious illness, caregiving, dying and bereavement go beyond the scope of professional health care services. Promoting health and wellbeing in these domains entails societal and civic responses complementary to health service responses. For instance, governments, health and wellbeing organizations, workplaces, schools, churches, neighbourhoods and health care services can collaborate to develop supportive social environments, policies, health services, skills and community action.

The worldwide Covid pandemic reminds us all of the importance of public health. This common pandemic experience should boost palliative care communities, associations or societies to make public health palliative care one of their main policy priorities. Palliative care clinicians and health care providers cannot solve all the problems of death, dying and bereavement by themselves, so they should collaborate more with community workers, social change workers, health promoters, sociologists, city planners, adult educators, public health professionals, etc. in order to design and develop, in co-production with local communities, societal solutions to the major challenges around serious illness, caregiving, dying and bereavement.

Thanks are due to our Scientific Committee for putting together an excellent program with content for all. Our plenaries, themed sessions, oral presentation sessions and poster sessions include diverse speakers from a wide range of countries and continents, presenting important topics related to public health and palliative care.

And thanks are due to you all for coming to the PHPCI 2022 conference in Bruges and for your dedication to the field of public health and palliative care.

We look forward to interacting with all of you at the conference in Bruges!

Luc Deliens



Joachim Cohen



Joint chairs of the Scientific Committee

7th World Congress of PHPCI

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## Programme abstracts

### Abstract ID: 20

**Abstract Type: Free Communication - Health Promoting Palliative Care**

### The First Oxford Textbook of Public Health Palliative Care

*Julian Abel<sup>\*1</sup>, Allan Kellehear<sup>2</sup>, Libby Sallnow<sup>3</sup>*

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The First Oxford Textbook of Public Health Palliative Care is a significant step forward in the development of the whole field of palliative care. In this text, we cover the case for public health palliative care, basic concepts and theory, basic practice methods, population based approaches, the evidence base and education and training. It is an extensive text written by 44 contributing authors who are internationally recognised specialists in their field.

We specifically examine the role of the 'new' public health, sometimes also known as health promotion. Health promotion is a major departure from the emphases on surveillance, disease, and health services by placing its gaze and efforts on practice solutions, health and wellbeing, and community and civic involvement in healthcare – in this case, palliative care. This Oxford Textbook of Public health Palliative Care is an introduction to this dimension of practice.

In addition, how to involve the community has at times been eclipsed by the need to establish the credibility of clinical practice. 'Community' often became places from which to recruit volunteers, raise funds and awareness of the new service, and locations to deliver new forms of day care or home care. The direct service emphasis had gradually distorted our understanding of 'community' by often making this appear singular rather than plural, by making it appear as target and receiver rather than partner and participant, by locating it on the periphery of care instead of understanding its necessary and central position.

### Competing Interests

The editors of the book received a fee for their work and have a royalty interest.

### Abstract ID: 21

**Abstract Type: Free Communication - Policy and Vision**

### Through the looking glass: what's on the other side of palliative care guidelines?

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**Background:** The publication of WHO guidelines has had international influence in the development of pain relief and palliative care strategies. Despite some progresses towards development in some countries, palliative care services continue to be largely unequal, mainly limited to high-income countries. To facilitate the development of palliative care, especially in low and middle-income countries, WHO has published guidelines to advise on implementation. However, questions remain on the extent to which these efforts help address implementation challenges. This research aims to bring critical attention to the deep-seated assumptions within WHO guidelines.

**Method:** This research was conducted by applying What's the Problem Represented to Be? framework to WHO guidelines. In this research, the WPR was conducted as follows: Discourse analysis to identify problem representation – what is proposed as 'change' signals how the problem is represented. An archaeology analysis was conducted to identify the concepts, knowledge and assumptions that constitutes the identified representation; genealogy traced the practices and discourses that allowed this representation of the problem to emerge; identification of silences; analysis of effects of representations such as ways of thinking, subject positioning and consequences for practice.

**Findings:** The representations identified within guidelines from 1990 to 2018 conceptualized as 'inadequacy' and 'inequality' suggests a constricted understanding of 'palliative care'. The first representation is deeply rooted in clinical efficiency of pain relief and symptom management, while the second focuses on increasing services to address structural inequalities rather than improving care. Both representations contribute to leaving the cultural and social dimensions of 'palliative care' unchallenged. Questions on

equity and colonialism are downplayed to emphasize the clinical efficiency and cost-effectiveness of palliative care measures.

**Conclusion:** Rather than contributing to a 'global' perspective of palliative care, the guidelines contribute to constrict palliative care to the realm of therapeutics and professional expertise. This indicates that current efforts from WHO remain contributing to leaving deep-seated premises unchallenged.

**Abstract ID: 23**

**Abstract Type: Workshop**

**The Mallon Micro-model: creating and maintaining compassionate communities when someone is dying at home**

**Annetta Mallon**<sup>\*1,2,3</sup>

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A compassionate community for someone who wishes to die at home requires at least 16 people in a network – but there are no standardised approaches to forming and maintaining these small-scale, micro networks. The macro/meso Abel model of compassionate communities has been fundamental in informing public policy and driving social change in terms of compassionate community and city formation; however, the micro level (for a domestic, small-scale compassionate community) is absent. Based on original research undertaken with end of life doulas in four countries, a micro model for forming, facilitating and maintaining compassionate communities when someone wishes to die at home has been developed. Not only does this model fill the gap in Abel's original template, but as it is simple in design and standardised it is easy to reproduce, and permits a good deal of flexibility for those in a caring network around someone at end of life. In this workshop, all three roles in the Mallon compassionate community micro model will be explained and explored from a variety of personality, task, and relationship perspectives. Included in the workshop are opportunities to explore what shifting roles can look and feel like for individuals within the micro compassionate community network, how to avoid carer burnout with the model, and how friends and family of those at end of life can contribute in ways that are meaningful and appropriate to their own needs. End of life doulas as well as health workers will benefit from this model, as it functions for expected,

terminal illness deaths – including voluntary assisted dying (VAD) which take place in the home. By the end of the workshop participants will understand all three roles, be proficient in the way the model functions as a whole, and be skilled and ready to incorporate the model into their end of life care work and practices.

**Abstract ID: 24**

**Abstract Type: Free Communication - Community engagement and development**

**Dying at home - a functional micro compassionate community model to avoid burnout and build networks**

**Annetta Mallon**<sup>\*1,2,3</sup>

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**Background:** after working as an end of life consultant and researching end of life doula (EOLD) practices in Australia, Canada, the UK and the USA it became apparent that nowhere in the world is there a standardised, readily replicable micro-model approach to compassionate community formation and facilitation for those who wish to die at home. Non-medical end of life workers, including EOLDs interviewed by the author, rely on ad hoc approaches and personal methods which take time to personalise for every individual situation. A qualitative research project was designed to find out what EOLDs think about compassionate community formation (facilitators and obstacles), and how they think their clients see them as lynchpins for death literacy and compassionate community advocates.

**Methods:** audio recorded semi-structured interviews took place via Zoom (with the single exception of a face-to-face interview in Australia), the transcribed recordings were returned to participants for editing and final approval and thematic analysis was undertaken of the approved transcripts.

**Results:** while supporting people in a non-medical role at end of life in a variety of locations, including homes, EOLDs rely on ad hoc and highly personalised approaches to compassionate community formation for each home death (and to a lesser extent hospice/aged care facility (ACF) deaths. This ad hoc approach takes time and energy to accomplish and may act as a distraction from the work of focusing on the needs of the person at end



of life, and a standardised, readily replicable model will fill an information and practice gap.

**Conclusion:** a three-level micro-model for compassionate community formation and facilitation was developed based on the findings from the research project. Personality type, relationship to the person at end of life, work/personal schedules and energy levels are all accommodated in the Mallon model, offering a standardised approach to functional, practical compassionate communities when someone is dying at home.

**Abstract ID: 25**

**Abstract Type: Poster – COVID**

**Are we now more empathetic, compassionate, and understanding towards difference?**

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At the end of September 2021, almost 5 Million people had died over the world due to Covid-19. These numbers do not consider the increase in suicides observed especially in youth due to pre-existing mental illness, or related deaths due to poor access to health, discrimination, social, and economic barriers.

It is vital to ask ourselves: Am I more aware of my privilege? Am I more understanding of the disadvantages that other members of my community and the world (immigrants, homeless, mentally ill, isolated) may face everyday? How will I apply my new knowledge to my Palliative/Bereavement care Practice?

We have to consider that the social determinants of health (Income and social status, Social support networks, Education and literacy, Employment/working conditions, Social environments, Physical environments, Personal health practices and coping skills, Healthy child development, Biology and genetic endowment, Health services, Gender, Culture) make a huge difference on how we have been impacted by this pandemic.

In this workshop we will create a safe space to reflect on our own experiences. We will learn from each other. We will develop an increased awareness on how to better support our communities every day.

**Abstract ID: 27**

**Abstract Type: Poster – Loss and Grief**

**The Wind Telephone**

*Mo Blishen<sup>\*1</sup>, Dawn Pegram<sup>2</sup>*

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**Background:** A disconnected rotary phone for ‘calling’ lost loved ones offered a unique way of dealing with grief in disaster-stricken Japan. I decided to set one up in my local street in New Zealand.

**Method:** I got an old rotary phone and had a containment constructed to house it on the beach in my street. I used qualitative methods to get information about how people felt about the phone.

**Results:** Overwhelmingly positive feedback about the phone.

**Conclusions:** Expressions of grief and methods of relief come in strange packages.

<https://procaffenation.com/did-you-know-a-telephone-booth-connects-people-to-the-dead-ones/>

<https://www.stuff.co.nz/dominion-post/news/101835768/phone-booth-on-wellingtons-south-coast-allows-people-to-call-the-afterlife>

**Abstract ID: 28**

**Abstract Type: Free Communication - Volunteers and compassionate neighbors**

**Hospice Volunteers in Europe and North America: Who Are They and What Do They Experience?**

*Caroline Varay<sup>\*1</sup>, Olivier Lareyre<sup>2</sup>, Carolina Baeza-Velasco<sup>1,3,4</sup>*

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**Background:** The need for support at the end of life continues to grow with the development of chronic diseases, which are the leading cause of mortality in the world. Volunteers are an integral part of the palliative care system, but these essential players are largely unknown.

**Aims:** The aim of the present work was to review literature concerning organizational aspects, psychosocial aspects, and issues for the future of hospice volunteering in Europe and North America.

**Methods:** This review is based upon a search conducted in scientific online databases supplemented by manual searches.

**Results:** The organizational context of hospice volunteering in the countries studied is heterogeneous. For example, the regulations, the places of intervention, the role and the training of volunteers vary widely. However, the psychosocial profile of volunteers and the experience of their involvement seem similar. Volunteers are most often women, at least 55 years old, empathetic, with traits of agreeableness, extraversion, openness and emotional stability. They perceive their involvement as fulfilling, despite difficulties related to the delimitation of their role, communication and integration into the care team. Meeting these organizational and emotional needs appears to be a current challenge as it would contribute to sustain the commitment and increase the number of these essential actors.

**Conclusion:** This study provides scientific elements which may be useful for the selection, training and support of hospice volunteers. More broadly, this research attempts to contribute to the dissemination of palliative culture by broadening knowledge about the people involved.

**Abstract ID: 29**

**Abstract Type: Free Communication: Community engagement and development**

### **Using a participatory community development approach within a paediatric children's hospice in Queensland, Australia**

*Peter Westoby<sup>1\*</sup>, Elham Day<sup>2</sup>, Paul Toon<sup>3</sup>, Kelly Oldham<sup>4</sup>, Fiona Hawthorne<sup>5</sup>*

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This presentation is both a story of participatory community development (CD) practice within the paediatric palliative care and bereavement space - and a portrayal of phenomenological reflective practice. The story and portrayal are about a

tradition of work – understood as participatory community development (CD) – amplified, made more visible and alive by a phenomenological reflective practice.

The presentation will examine the rationale for using a participatory community development approach to sit alongside the traditional service-delivery work of a children's hospice - Hummingbird House, a 5-year-old hospice, mandated to work within the whole of Queensland, Australia.

The paper will consider how reflective and therefore adaptive practice ensures that the participatory community development approach remains responsive to the voices of families engaged by Hummingbird House (families whose children have life-limiting illnesses) and responsive to partnerships established (with neighbourhood centres; local government authorities and so forth). The community development program framework will be explained and some case studies of grounded projects will be shared. Initial evaluation data, from Queensland University of Technology (QUT), will also be presented.

**Abstract ID: 31**

**Abstract Type: Free Communication - Community engagement and development**

### **Putting your house in order: Finding the carrot for community engagement on dying, death & bereavement**

*Rebecca Lloyd<sup>\*1</sup>*

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**Background:** A growing body of literature, policy and practice has emerged about end-of-life care in recent years. Nonetheless, there are few concrete, repeatable examples offered in this field. In this research, we present a method of involving communities in end-of-life planning. The Putting Your House in Order (PYHIO) workshops are intended to inspire, educate, and empower communities. The program aims to raise awareness in the Irish public about end-of-life wishes and to educate people who care about them about how to communicate those wishes. As part of our partnership with Age Friendly Ireland, we designed the event to encourage a positive dialogue, to give people the opportunity to ask questions, to seek advice, and to clarify any concerns they may have about end-of-life planning.



**Method:** A community-based assets approach means local people led PYHIO and hosted within their communities. Community members also arrange refreshments and invitations. The sessions followed a similar format each day, with an end-of-life expert, a solicitor, and an official from the health service presenting information, along with time for questions and comments. Six talks were held throughout County Clare and Seven throughout County Limerick to over 1000 members of Age Friendly Ireland.

Monitoring and evaluation of each event identified what worked well and what needed to be improved. There was a range of findings from the practical – not being able to hear at the back of the room, more time for questions, to the profound, children managing parents' affairs after dementia rendered them incapable.

**Conclusion:** Feedback from participants confirmed the right approach in planning and implementing the sessions. Participants reported they gained a better understanding of how to plan ahead, with many expressing surprise at how straightforward it was. Participants commented on the delivery of the talks being compassionate and empathetic, which helped them to deal with their fears and to engage. Learning about others' experiences also helped them.

IHF and AFI are collaborating on the PYHIO project with the goal of establishing talks in every county of Ireland by 2022. This initiative has won an award for age-friendly innovation in 2020.

**Abstract ID: 32**

**Abstract Type: Workshop**

### End of Life Aid Skills for Everyone (EASE)

*Rebecca Patterson\*<sup>1</sup>, Caroline Gibb<sup>1</sup>, Mark Hazelwood<sup>1</sup>*

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**Objective:** This workshop will give delegates the opportunity to experience an excerpt from the End of Life Aid Skills for Everyone (EASE) course, and to learn about its aims, approach, development and delivery model.

**Overview:** Family, friends and communities have an important role to play in providing informal support when someone is faced with deteriorating health, caring responsibilities, death or

bereavement. However, unless individuals and communities have a certain level of end of life literacy, they will lack the confidence and skills to offer this support.

Public education is one example of a public health approach to palliative care that can be used to develop individual skills and knowledge about various aspects of death, dying and bereavement. There are many ways to approach public education. In Scotland the Scottish Partnership for Palliative Care has developed End of Life Aid Skills for Everyone (EASE).

EASE is a course designed to enable people to be more comfortable and confident supporting family and community members with issues they face during dying, death and bereavement.

It is delivered free of charge by volunteer EASE Facilitators, and takes approximately 8-12 hours to complete over a period of four weeks, either face-to-face or online.

It is designed for members of the public, and welcomes adults of all ages, experiences and walks of life.

**Learning outcomes:** This workshop will explain why the SPPC chose this particular approach to public education, and give an overview of the development process, delivery model, feedback and learning so far. To allow delegates the opportunity to reflect on the value of this approach, we'll run an hour's excerpt from the course, with plenty of opportunities for delegate interaction.

**Abstract ID: 33**

**Abstract type: Free Communication - Family caregiving**

### A systematic review of concordance and discordance between people with advanced illness and their caregivers in palliative care

*Sophie Mulcahy Symmons<sup>1</sup>, Karen Ryan<sup>2,3,4</sup>, David Mockler<sup>5</sup>, Samar Aoun<sup>6</sup>, Andrew Davies<sup>1,4,7</sup>, Lucy Selman<sup>8</sup>, John Lombard<sup>9</sup>, Suzanne Guerin<sup>10</sup>, Nicola Cornally<sup>11</sup>, Michael Connolly<sup>7,12</sup>, Regina McQuillan<sup>2,13</sup>, Norma O'Leary<sup>7,14</sup>, Mary Rabbitte<sup>15</sup> and Geraldine Foley\*<sup>1</sup>*

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**Background:** Family caregivers participate in decision-making in palliative care. Patients and family caregivers can have both similar and different preferences for care. However, what underpins concordance and/or discordance between patients and family caregivers in decision-making in palliative care is not well understood.

**Objectives:** To identify key factors which underpin concordance and/or discordance between patients and family caregivers in decision-making in palliative care.

**Methods:** A systematic review of original studies published in full between January 2000 and June 2021, was conducted. The search and extraction were carried out in line with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). Databases used included Embase, CINAHL, Medline, AMED, PsycINFO, PsycARTICLES, Web of Science, and Social Sciences Full Text. A narrative synthesis of the selected studies was undertaken.

**Results:** Thirty-nine studies met inclusion criteria after full text review. Studies focused on patient and family caregiver preferences for patient care as opposed to family caregiver formal support and care. Patient illness progression and patient and family caregiver recognition and/or acceptance of patient impending death, were key factors that fostered consensus between patients and family caregivers. Discordance between patients and family caregivers was underpinned by relational conflict and by a lack of open communication between the patient and family caregiver about each other's preferences for care.

**Conclusion:** Patients and family caregivers in palliative care can approximate to each other's preferences for care. Research on patient and family caregiver concordance and discordance pertaining to family caregiver formal supports warrants investigation. Interventions focused on aiding patients and family caregivers to communicate openly with one another about each other's preferences for care could prove beneficial for both patients and family caregivers.

**Abstract ID: 35**

**Abstract Type: Workshop**

## **The Truacanta Project: supporting compassionate communities**

**Rebecca Patterson<sup>1</sup>, Caroline Gibb<sup>\*1</sup>, Mark Hazelwood<sup>1</sup>**

<sup>1</sup>Scottish Partnership for Palliative Care

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**Objective:** This workshop will give delegates the chance to learn about the background, aims and development of The Truacanta Project; to hear from representatives of the Truacanta communities about their experiences of building compassionate communities in Scotland; and to participate in an interactive creative visioning exercise.

**Overview:** The Truacanta Project is a compassionate communities, community development initiative run by the Scottish Partnership for Palliative Care and funded by Macmillan Cancer Support. The project was set up in 2019 to support local communities across Scotland who are interested in taking community action to improve people's experiences of death, dying, loss and care.

The focus of a local project and the actions taken are determined by the community themselves. However, being part of the Truacanta Project gives local community projects access to:

- community development support and advice
- networking and learning opportunities
- support with evaluation

The project began in May 2019 by asking for expressions of interest. A shortlist of eleven were then supported for six months to create a vision for change, which became a formal application to be part of the project.

The final five projects were selected in January 2020, with the aim of launching the local projects in May 2020. Each of the five projects has therefore faced the challenge of starting to build a compassionate community during a pandemic, and each project has their own story to tell about their successes, opportunities, challenges and hopes.

**Learning outcomes:** At this workshop delegates will learn about the Truacanta model for building compassionate communities, why it was chosen and what evaluation indicates thus far. Delegates will also hear first-hand how local experiences of a national project have been, and will have the chance to understand some of the approaches used in development of the Truacanta Project through participating in a creative visioning exercise relevant to their own context.

**Abstract ID: 36**

**Abstract Type: Poster – ACP & End of Life communication**

**Medical end-of-life decision-making in a small resource-poor Caribbean country: a mortality follow-back study of home deaths**

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**Background:** In resource-poor countries, including in Latin American and the Caribbean, empirical information about the characteristics and incidence of medical end-of-life decisions (MELDs)—withholding or withdrawing potentially life-prolonging medical treatments—is largely absent.

**Methods:** The aim was to describe the incidence and decision-making characteristics of MELDs taken prior to the death of people who died at home in Trinidad and Tobago (T&T). A mortality follow-back study was used where a representative sample of deaths occurring at home in 2018 was drawn from death certificates at the national death registry. The general practitioners who certified the deaths were sent a questionnaire.

**Results:** The sample consisted of 309 adult deaths and the response rate was 31% (N=96). Physicians were: mostly male (79.2%), practiced medicine for more than twenty-years (63.5%), had no formal palliative care training (69.8%). Non-sudden deaths represented 76% (N=73), of these, medications to alleviate pain and symptoms in the last 7 days of life were administered in

65.8%, including opioids 21%. Potentially life prolonging treatments were withheld in 9.6% but none withdrawn. No physician/patient discussions about various end-of-life treatment options occurred in 61.6%. Compared to physicians with no formal training in palliative care, those with training more often: prescribed or administered opioids in the last 7 days of life (35.7% vs. 11.1%,  $P=0.01$ ), had discussions with patients about end-of-life treatment options (60.7% vs. 24.4%,  $P=0.002$ ), and discussed medication use to alleviate pain and other symptoms with patients (50% vs. 17.8%,  $P=0.004$ ).

**Conclusions:** Differences in the care and treatment general practitioners provided to their patients could be associated with them having been formally trained in palliative care. The necessary support to further develop palliative care in T&T is needed.

**Abstract ID: 37**

**Abstract Type: Poster - Literacy & Education**

**Education for palliative representatives increases the quality of palliative care**

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**Background:** The coverage rate in the Swedish palliative care register shows that Uppsala County is third from the end nationally according annual report (2019). The palliative care team (PKT) in Uppsala has a county-wide assignment to educate care staff regardless of professional title and employer in palliative care. All care units must have at least one palliative care representative who passes the knowledge forward about palliative care. In order to achieve good quality palliative care in Uppsala County in accordance with the National Board of Health and Welfare's quality indicators, PKT identified a need for competence development.

**Aim:** How are the working methods and level of knowledge of care staff affected by an education directed to the palliative care representatives in general palliative care?

**Method:** PKT designed and carried out a pilot project in the spring of 2021 in Östhammar municipality. Due to the pandemic, it was carried out digitally. The participants chiefs were informed before the

education to facilitate implementation. In preparation the participants; nursing staff, paramedics and nurses were asked to complete the online education “Palliation ABC” (web-based learning platform). The education was divided into two occasions; a full day + a half day. On the first day, all representatives participated, on the second day, only nurses participated. They received a copy of educational material created by PKT; “POFF”; Palliative care in pocket format and the booklet “Palliative care at the end of life”. The material contains various symptom relieving nursing measures for common symptoms in the end of life, a comprehensive description of the division of responsibilities in palliative care and a structured symptom assessment model. The education was based on the material and the representatives passed forward the knowledge to their colleagues, who also each received the material. Monthly reconciliations with the representatives were carried out after the education, as well as sending out monthly letters.

**Results:** Follow-up review of the municipality’s data in the Swedish Palliative Care Register shows overall improved results after completing the project.

**Conclusion:** An educational effort in the form of representative education increases the knowledge in general palliative care among care staff.

**Abstract ID: 43**

**Abstract Type: Poster – Health Promotion**

### Exploring a Public Health Palliative Care Approach to Emergency Medical Services

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**Background:** Emergency Medical Services (EMS) are a highly skilled and unique workforce, attending to patients in the community 24 hours a day, seven days a week across low, middle and high-income countries. As global populations continue to age and community preferences to die at home are increasing, new models of community-based EMS are evolving to include palliative and end-of-life care. This broadening of scope challenges the traditional role of EMS – to deliver emergency care and transportation to

hospital – and highlights an unharnessed public health asset of adjunct palliative care delivery available to health systems worldwide. However, the way in which EMS can best fit into a public health palliative care approach remains unknown.

**Methods:** Through reflective discussion we draw upon the skills and perspectives of an international team of EMS, public health and palliative care researchers to discuss the potential role of EMS in a public health palliative care approach. Employing a South African and Australian lens, the key objectives of the study include (1) delineating current public health palliative care frameworks involving EMS provision of palliative care, (2) discussing the utility of EMS use in a public health palliative care approach, (3) identifying and discussing barriers preventing public health approaches to EMS palliative care provision, and (4) outlining a way forward for future research, policy, education and practice.

**Results and conclusion:** Public health palliative care policies addressing EMS are absent in both South Africa and Australia. Integrating EMS into a public health palliative care approach could achieve greater palliative care equity, access and integration across multidisciplinary teams. However, a range of structural, cultural and practice barriers are hindering EMS from becoming involved. A comprehensive framework recognising the role EMS can play in public health approaches to palliative care could help develop stronger models of integrated care delivery and reduce health inequalities amongst palliative patients.

**Abstract ID: 44**

**Abstract Type: Poster – Cancer**

### Experience from the use of oxycodone / naloxone versus morphine in the treatment of severe cancer pain in palliative care in the Republic of North Macedonia

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**Background:** oxycodone / naloxone is a well-known strong opiate analgesic, which can be administered as the first strong opiate analgesic



when weak opiate analgesics are no longer effective, or when other strong opiate analgesics are ineffective. In case of insufficient analgesia and / or intense side effects such as sedation, hallucinations and nausea / vomiting, switching from another opioid to oxycodone / naloxone may be helpful. It became available in our country in 2018 as the first strong oral opiate analgesic with prolonged action. Its benefits have been felt by many patients with severe cancer pain, who had previously been on an injectable form of morphine, which was the only one available in our country. To compare the quality of life of patients between oxycodone / naloxone and morphine in routine clinical practice.

**Methods:** A total of 151 patients requiring 24-hour opioid pain treatment were screened for morphine or oxycodone / naloxone (1: 1) therapy. The changes were monitored until the 10-th week, in assessing the quality of life, used EQ-5D-5L, which consists of EQ-5D descriptive analysis, and EQ-VAS visual scale.

**Results:** The EQ-5D-5L score showed a significant improvement in the quality of life of all patients over 10 weeks, but with a significantly larger difference (73% vs. 27%) than oxycodone / naloxone. There was a significant difference with respect to EQ-5D (approximately 95% of patients) showing significantly better parameters (mobility, care independence, routine activities, presence of pain, and presence of anxiety / depression).

**Conclusion:** Treatment of severe cancer pain with strong opiate analgesics significantly improves quality of life during 10 weeks of follow-up. In the study group, treatment with oxycodone / naloxone compared with morphine showed significantly better results.

**Keywords:** oxycodone/naloxone, strong opiod analgetics, quality of life

**Abstract ID: 45**

**Abstract Type: Free Communication - Compassionate communities research**

**Compassionate communities approaches to end of life care as a Therapeutic Landscape**

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**Objective:** to share research findings and extend understanding of compassionate communities Public health approaches within palliative and end of life care has gained momentum, in particular compassionate communities as one of the components of the concept. However, there is limited evidence of how compassionate communities are being implemented. This original empirical research study explores and extends the understanding of compassionate communities approaches in the UK. A qualitative case-study design includes three different research sites providing palliative care services, two are hospices and one is a community organisation. The main data collection methods include semi-structured interviews and focus groups exploring the perspective of: people living with a life limiting condition at end life (primary participants), their family members, friends, volunteer befrienders, community palliative care nurses, care coordinators, chaplain, bereavement counsellor, compassionate communities coordinators, community worker and organisation leaders.

Although, there are differences in the compassionate communities approaches across all three sites as defined by research participants, this research study has identified shared characteristics. The first characteristic is home as the preferred place of care with physical, social and psychological symbolic meanings; second is of formal and informal care interface within and across inner and outer circles of care; third is the essential role of volunteer befriender within the inner circle of care strengthens the interface between formal and informal care. The participants considered the relational aspect of and between formal and informal care to be important. These characteristics are elements found within Therapeutic Landscapes, site-specific places with healing properties and/or the maintenance of health and wellbeing. This research study frames the concept of a compassionate communities approach within the theoretical framework of a Therapeutic Landscape, extending the understanding of a compassionate communities.

**Abstract ID: 46**

**Abstract Type: Poster - Family caregivers**

**Empowerment of carer in outpatient home care through small chunks of accessible intel**

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**Background:** Taboo on the subject matter of palliative care seems to be myriad. Particularly once the word ‘palliative’ is mentioned most, health professional or not, tend to freeze. Tiptoeing around the matter. Walking on egg shells. A feeling of awkwardness tends to surface amongst many carers. That feeling is amplified by cultural or societal mindsets existing around dying, and/ or by the misguided notion that once curative treatments stop palliative care means one will die within weeks.

But it might also, or rather on top of those, be derived from the insecurity regarding all that entails palliative care. For instance: How do I open a conversation with both family and doctor on advanced care planning (DNR, will statements. . .), on what the patient wishes in the (mostly unknown) remaining time of their life? How do I spot the phase in which a patient is entering their end of life care stage?

On a meso level, as an outpatient home care organization (Wit Gele Kruis Oost-Vlaanderen), it leaves us with a significant challenge: how do we empower our care staff to the extent it doesn’t generate more admin which could become so time consuming it overtakes their care time?

**Aim:** Empowerment of the carer through small chunks of accessible information.

**Methods:** After reviewing of the present information flow internally by using the indicators, such as ‘how up to date’, ‘which relevance’, ‘how accurate’, and pinpointing the strong points and challenges around processes, documents, systems, internal information flows we came up with an action plan.

Keeping in mind some of the organization’s quality indicators such as promoting lifelong learning and informing the stakeholders, it came only natural to design a yearlong information flow.

To prevent ourselves from tapping only into top down information we established focus groups with the specialized teams and with a few individuals from our local teams asking them to grant us feedback on the contents of our intended information and on the manner of distributing that intel.

**Results:** (by Autumn 2022)

A one year long information flow:

- Information through different channels with background, but mostly practical tips and tools, eg.:
- Triggers to recognize a palliative care situation at home
- Understanding the difference with the triggers for end of life care
- Comfort care explained
- Pain therapy with and without medication therapy
- Tips on communication with the patients, its family/ informal carer and the general practitioner
- Information on law & regulations (will statements, authorization, assisted dying/ euthanasia, DNR, advanced care planning, palliative care bonus, palliative care leave, etc)
- Smart tree (or Flow Sparks) questionnaire to get informal feedback
- E-newsletter for general practitioners
- Implementation of the PICT scale into the electronic patient file/ intranet
- Emphasis on the surprise question
- Installation of the LEA app (LEA Levenseinde App) from LEIF (www.leif.be) on the tablets (+ introductory note on the weekly newsletter on how to use it)
- The commitment of the care department to establish a ‘theory’ reminder each year around the day of (Oct 9th)
- Onboarding trajectory for new personnel: revised intel

### Prospected conclusion:

- A positive care experience for all stakeholders (doctor, nurse, informal carer, family, patient)
- Moving forward towards an integrated palliative care mentality

**Abstract ID:** 47

**Abstract Type:** Free Communication - Community engagement and development

### Forming a Citizen-led Community of Practice to Implement the Compassionate City Charter

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**Background:** In 2021 the National Health Service in England adopted six ambition statements to improve the quality and accessibility of support for people of all ages living with dying, death, loss and grief. Our work focussed on Ambition Six: 'Each Community is Prepared to Help'.

In the East of England, we aimed to establish a Citizen-led Community of Practice (CoP) to enact elements of the Compassionate City Charter to spread awareness of a public health approach to palliative and end of life care.

**Methods:** CoP members used an Asset Based Community Development (ABCD) approach to build on existing connections and relationships to support participatory action and learning. The core group of CoP members comprised representatives from local charities, schools, volunteer groups, special interest groups (e.g. dementia carers), the church, artists, end-of-life doulas, and the town council.

We used 'Contribution Analysis' to evaluate citizens' responses to this approach. We performed a context mapping exercise at the start and co-developed our outcome framework together. Data collection used six constructs: Charter Activities, Network Building, Experience of Convening a Citizen-led CoP, Changes in Knowledge, Skills and Community Capacity, Changes in Policy or Practice, and Perceived Value.

**Results:** Over 12 months CoP activities included: inviting local residents to generate a 'treasure map' of their area via a community asset walk, launching a bereavement cookbook with stories of living with grief, organising a memorial event hosted by the local forest school, training volunteers to act as community connectors, joining forces with a mental health charity to offer support during COVID, liaising with primary schools to implement a 'remembrance heart' project (reflecting on experiences of loss), and training citizens to become 'conversation partners' to support members of the public with advance care planning. Our activities were transformed into a narrative performed to music by a street poet, and an audio play was written by a CoP member.

**Conclusion:** The Citizen-led CoP was well-received by all. Members embraced this new way of working. There was a good interface with statutory services that enabled a local resident to die

at home following a rapid transfer from hospital. We aim to spread this practice across our region.

**Abstract ID: 48**

**Abstract Type: Free Communication - Loss and grief**

### **Black Doulas Matter: Exploring the Intersection of Black Lives, Black Death and White Supremacy**

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Grief, loss, death, and dying are a part of life – for all of us. Influenced by many factors, including but not limited to culture, religion/spirituality, personal history, and circumstances surrounding the death, those experiences will vary from person to person. Are there unique factors that influence how people of African descent grieve? How does the parasitism of whiteness impact the grieving of Black People? Anticipatory grief, the loss of a loved one- particularly from malicious acts of violence, disenfranchised grief, generational trauma, and the lack of social support place people of African descent at risk for continuous chronic grief reactions.

Furthermore, we often ignore grief and outsource care for the dying to medical professionals, who sometimes view death as failure. But there is a deep historical and spiritual tradition of sitting with and being transformed by grief and doing death differently—of guiding the dying in a way that allows for an authentic reconnection to self, and in many cases, a more peaceful death. In this workshop, you will name your losses, explore your mortality, learn foundational principles of death midwifery, identify how whiteness impacts Black grief, reimagine personal and communal healing and build your confidence to journey with those at or near the end of life- especially those in marginalized communities.

**Abstract ID: 49**

**Abstract Type: Poster – Various Topics**

### **Needs for timely palliative care in older patients with non-malignant diseases: a multicentre qualitative study**

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**Background:** Nonmalignant diseases are the main cause of death for the elderly population in many Western countries who are also at a high risk of developing multimorbidity. However, the provision of palliative care for them remains inadequate resulting in unmet needs in patients and carers.

**Aims:** To explore palliative care needs of patients and carers, and factors affecting timely palliative care delivered by health professionals in routine practice.

**Methods:** A multicentre qualitative study was undertaken across England, Scotland, Spain, Portugal and Greece in both disease-specific and specialist palliative care services. Patients with severe chronic obstructive pulmonary disease, idiopathic pulmonary fibrosis, frailty, comorbidities and multimorbidity, carers and health professionals were recruited. Data were collected using semi-structured interviews and analysed using framework analysis. Themes were synthesised and generated using the constant comparison process.

**Results:** A total of 66 patients, 28 carers and 63 health professionals were interviewed. Patients and carers expressed insufficient support, psychosocial consequences, limited knowledge of palliative care, while health professionals described heterogeneity in palliative care services, lack of reliable screening tools and needs assessment and incoherent support for patients and carers. Needs for reassurance, rapid service access, psychological care, financial support with enhanced communication skills and effective referral pathways were perceived important for timely palliative care support.

**Conclusion:** Patients and carers have unmet needs for managing their progressive conditions, psychosocial and financial impact, although

models of palliative care delivery vary largely. Timely but needs-based palliative approaches are needed with reliable identification and needs assessment tools.

**Abstract ID: 50**

**Abstract Type: Symposium**

### **Leaving no one behind: providing Palliative care in humanitarian settings**

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Mhoira Leng<sup>2,4</sup>**

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**Target Audience:** Palliative care practitioners (doctors, nurses, psychologists, social workers and other members of the palliative care multidisciplinary team) who are interested in learning about and/or providing palliative care in humanitarian crises.

**Learning Objectives:**

- To identify the role of palliative care and the specific palliative care needs of individuals affected by humanitarian crises
- To identify challenges and potential solutions to the provision of palliative care in humanitarian crises
- To describe examples of successful integration of palliative care into humanitarian crises

**PallCHASE Symposium Panel:**

Joan Marston: South Africa/ Ukraine, Mhoira Leng: UK/Uganda, Megan Doherty: Canada/Bangladesh, Kathryn Richardson: MSF South Sudan

Palliative care is essential in humanitarian crises, whether due to conflict, natural disaster, epidemics or marginalised group, due to the large burden of human suffering and high rates of mortality. However, the needs of individuals with serious or life-limiting conditions are rarely considered when designing humanitarian health responses and access to palliative care is rarely available. Yet palliative care has been successfully integrated into the humanitarian response in some settings.

This symposium will include presentations from a panel of experts sharing their experiences of integrating palliative care into the response to humanitarian crises, with an emphasis on the palliative care needs of seriously ill individuals. The presentations will describe the role of palliative care as well as barriers and potential solutions to palliative care integration.

There will be an update from the role of palliative care networks (including PallCHASE) in coordinating an international palliative care response to the unfolding crisis in Ukraine. In addition, there will be needs identification surveys, educational and clinical palliative care programs from humanitarian settings in Uganda, Bangladesh and South Sudan. We will share lessons learned and opportunities to meet the current and future challenges in humanitarian palliative care.

Time to be provided for questions and answers.

**Abstract ID: 52**

**Abstract Type: Poster – Health Promotion**

**Development of a self-management eHealth program to support and empower people with advanced cancer and their family caregivers**

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\*\*'Evaluation of Dyadic Psychosocial Interventions for People with Advanced Cancer and their Informal Caregivers (DIAdIC): An international randomized controlled trial' – 'DIAdIC' (EU grant agreement No 825722)

**Background:** Ehealth programs are a promising way to support people with advanced cancer and their family caregivers. An intervention that has been proven effective in improving quality of life in patients and family caregivers is the nurse-led face-to-face FOCUS program, developed and tested in the USA. FOCUS was adapted to the health care context of six European countries (FOCUS+) and translated to a web-based format (iFOCUS). We aim to describe the

development of iFOCUS and the challenges we encountered during this process.

**Methods:** Development of iFOCUS encompassed seven steps: 1) defining the concept, 2) development of mock-ups and program content, 3) gathering feedback from an international consortium, 4) technological development of iFOCUS, 5) creating an iFOCUS version for each of the six European countries, 6) preliminary testing through functional and user testing and 7) implementing the final version in an international randomized clinical trial (RCT).

**Results:** iFOCUS is a psycho-educational eHealth program for people with advanced cancer and their family caregivers that is completed autonomously by the patient-caregiver dyad together. The program consists of four sessions spread over 12 weeks with three weeks between each session. Key characteristics of the program are psycho-educational character, addressing the FOCUS components, varied pedagogic approach, tailored, stimulating dyadic communication, complementary to regular care, and accessible. During development various challenges arose which were handled pragmatically. User and functional testing showed that the program functioned well and was acceptable to users. Minor changes needed to be made to the content, tailoring and program flow.

**Conclusion:** Developing a self-managed eHealth program has many challenges. Some pedagogic features are easier to incorporate in a face-to-face intervention due to the fluid nature of conversations. The program is now being tested in a large-scale international RCT.

**Abstract ID: 53**

**Abstract Type: Free Communication - Compassionate communities research**

**Researching Compassionate Communities from an interdisciplinary perspective: Development of a research framework**

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**Background:** 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 with 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.

**Abstract ID: 54**

**Abstract Type: Symposium**

## Lessons Learned during the COVID-19 and beyond Pandemic for Children Living with Rare Diseases, their Siblings, and Families

*Ulrika Kreicbergs<sup>1</sup> (chair/speaker), Charlotte Handberg<sup>2,3</sup> (speaker), Camilla Udo<sup>1</sup> (speaker), Maureen Lyon<sup>\*4,5</sup> (speaker)*

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Dr. Handberg will report on parents' perspectives on the impact of COVID-19 on the biopsychosocial health, daily activities, and quality of life among their children with neuromuscular diseases (NMD). Understanding the prevalence of COVID-19 infection and its impact, specific recommendations will be made for supporting vulnerable patients during a pandemic, which may be transferable to other contexts, countries, and chronic illnesses.

Little is known about how families including a child with spinal muscular atrophy (SMA) have experienced life during the COVID-19 pandemic. Dr. Udo's presentation will explore how parents and grandparents of children with SMA feel the COVID-19 pandemic has affected their lives, particularly as regards medication and rehabilitation of their child. Actions to create compassionate communities will be recommended for when societies and health care systems reopen.

Siblings of severely ill children with rare diseases are seldom seen or heard. Little is known about their situation in the family and in the community. To support them we need to understand their experiences. Interviews with siblings (aged 6 to 14 years) whose brother or sister had been cared for at a children's hospice were invited to participate. Dr. Kreicbergs and colleagues used four different communication tools to ease the interviews.

Dr. Lyon and key stakeholders adapted the Carer Support Needs Assessment Tool (CSNAT).



CSNAT (Paediatric) is a process for identifying and understanding the palliative care needs of family caregivers and of their children living with a rare disease. Pilot results will be presented from the CSNAT (Paediatric), administered during COVID-19. Lessons learned and action plans generated by family caregivers to support themselves and their children will be shared.

**Abstract ID: 55**

**Abstract Type: Workshop**

**Grief Literacy: How to Take it into Practice and Education**

*Lauren Breen<sup>1</sup>, Susan Cadell<sup>\*2</sup>, Amy Chow<sup>3</sup>, Karima Joy<sup>4</sup>, Daisuke Kawashima<sup>5</sup>, Phyllis Kosminsky<sup>6</sup>, Mary Ellen Macdonald<sup>7</sup>, David Roth<sup>8</sup>*

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**Background:** We are a group of researchers and clinicians, who, at an international meeting on death, dying and bereavement, developed the concept of grief literacy: an individual's capacity to access, process and use knowledge regarding the experience of loss. Grief literacy is a fundamental component of societies that value compassion and mutual support. While grief is universal, grief literacy will mean different things to different communities. Broad acceptance and implementation of grief literacy will depend on open communication that identifies the challenges and obstacles that must be addressed to promote awareness and inspire action aimed at creating more compassionate communities.

**Purpose and Approach:** Grief literacy belongs to everyone. The concept of grief literacy will be further developed and deepened through this workshop.

Participants should come prepared with their own examples of grief literacy.

In this interactive workshop, we will

- a) present our theoretical conceptualization of grief literacy as embedded in the public health paradigm.

- b) provide examples of how it has been used in practice and education.
- c) explore with the participants the concept in relation to their local socio-cultural specificity.
- d) work together with the international audience to imagine how best this concept can further enhance practice and education in multiple disciplines and fields.

Participants will:

- a) understand the paradigm shift signaled by the inclusion of grief literacy in public health palliative care.
- b) apply the concept of grief literacy to their own practice and teaching contexts.

Application to PHPCI:

Grief literacy augments the concept of death literacy, thereby enhancing the compassionate communities' approach. This workshop will prepare participants to best implement grief literacy in their classrooms and communities.

**Abstract ID: 57**

**Abstract Type: Poster - Cancer**

**Early referral to a palliative team improves end-of-life care among gynecological cancer patients**

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**Objective:** To assess palliative care involvement, chemotherapy use, and other interventions 30 days before death among patients with gynecological cancer, and to identify factors associated with chemotherapy use.

**Methods:** Clinical data on end-of-life care were retrospectively extracted from the medical records, a retrospective, population-based study.

All patients were primary treated at the Norwegian Radium Hospital. Place of death: 4 different hospitals ( $n = 48$ ), 15 different nursing homes ( $n = 87$ ) and home ( $n = 15$ ).

**Results:** All women with residence in Oslo, Norway who died of gynecological cancer 2015-2017 (36 months;  $n = 163$ , median age 70.1 years at death, range 26-100.) were identified. Ovarial- ( $n = 100$ ), uterine- ( $n = 40$ ), cervical- ( $n = 21$ ), vulvacancer ( $n = 2$ ).

Twenty-one percent ( $n = 21$ ) of ovarian cancer patients received systemic chemotherapy 30 days before death compared to 10% ( $n = 4$ ) of uterine cancer patients. Patients that had been referred to palliative team within 60 days seems to have a greater reduced risk of having systemic chemotherapy within 30 days before death OR 0.25 (95% CI 0.05-1.13) compared to referral within 30 days OR 0.68 (95% CI 0.16-2.83)). The most common surgical interventions are ascites drainage ( $n = 24$ ), pleural drainage ( $n = 16$ ), intraperitoneal mitoxantrone ( $n = 13$ ), gastric tube ( $n = 8$ ) and pyelostomy ( $n = 8$ ).

**Conclusions:** Early referral to palliative care seems crucial when we aim for less chemotherapy at end-of-life. Most of the surgical interventions are symptom relieving.

**Abstract ID: 58**

**Abstract Type: Free Communication - Health Promoting Palliative Care**

**How can a behavioral theory be used to gain insight into factors of health-promoting behavior during serious illness?**

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**Background:** Behavioral theories are often used to better understand and change health-promoting behaviors and develop evidence-based interventions. They can also be used to improve palliative care and increase the role of people who are confronted with serious illness. However, little is known about how to use behavioral theories to better understand and change palliative care behaviors in people who are confronted with serious illness. This paper wants to describe how behavioral theories can be used to gain insight into factors of health-promoting behavior in seriously ill people, using a case example of starting

a conversation about palliative care with the physician for people with incurable cancer.

**Methods:** We chose a behavioral theory. We applied and adapted this theory by performing 25 interviews with the target population. We operationalized the factors of this newly developed behavioral model based on surveys assessing health behavior factors and results of step 2. An expert group ( $n = 14$ ) checked content validity. We tested the survey cognitively ( $n = 8$ ). We identified the most important factors with a survey study ( $n = 80$ ) and logistic regression analyses.

**Results:** We selected the Theory of Planned Behavior. This theory was applicable to the behavior of starting a conversation about palliative care with the physician, but needed extending (e.g. knowledge). The final survey that was filled out by people with incurable cancer included 131 items on psychosocial and perceived social environmental factors. The results of the survey showed that attitudinal factors were the most important factors associated with starting a conversation about palliative care with the physician or having the intention to do so.

**Conclusion:** This paper describes a method applied to a specific example, offering guidance for researchers and practitioners interested in understanding and changing a target behavior and its factors in seriously ill people and in improving patient empowerment.

**Abstract ID: 59**

**Abstract Type: Poster - Various Topics**

**Recruitment and retention in palliative care trials: challenges and strategies**

*Anne van Driessche<sup>\*1,2</sup>, Kim de Nooijer<sup>1,2</sup>, Vincent van Goethem<sup>1,3</sup>, Orphé Matthys<sup>1,3</sup>, Kim Beernaert<sup>1,3</sup>*

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In recent years, the number of trials evaluating effectiveness of multi-component palliative care interventions for people with life-threatening illnesses and their families has increased. One of the main challenges in conducting multi-component palliative care trials, is successful participant



recruitment and retention in a vulnerable population already experiencing high levels of distress. These challenges may lead to delayed availability of beneficial interventions, increased trial costs and time and inconclusive trial results.

The aims of this symposium are: 1) to present current challenges in recruitment and retention and strategies to overcome them based on three multi-component palliative care trials conducted by the presenters; 2) to exchange experiences and reflect on potential strategies to improve recruitment and retention in multi-component palliative care trials together with the participants of this symposium.

The 3 multi-component palliative care trials are: 1) Frailty+: a timely short-term specialized palliative care service intervention for older people with frailty and complex care needs and their family in primary care, aimed at reducing their symptom burden evaluated in a pilot randomised controlled trial (RCT). Recruitment period: February – December 2020 (participant follow-up 2 months). 2) DIAdIC: two psychoeducational interventions for people with advanced cancer and their family caregiver: FOCUS+ (a nurse-led face-to-face intervention) and iFOCUS (a self-administered webtool), aimed at improving patient-family caregiver dyads' quality of life, evaluated in an RCT in 6 European countries. Recruitment period: February 2021 – September 2022 (follow-up 6 months). 3) BOOST pACP: a paediatric advance care planning (ACP) intervention for adolescents with cancer and their parents aimed at improving parent-adolescent communication on ACP themes evaluated in a multi-centre RCT. Recruitment period: February 2021 – February 2023 (follow-up 7 months).

**Abstract ID: 61**

**Abstract Type: Symposium**

### **Social, Political, and Interpersonal Power and Access to Hastened Death Speakers**

*Jane Lowers<sup>\*1</sup>, Claudia Gamondi<sup>2,3</sup>, Victoria Ali<sup>2,4</sup>, Janette Fish<sup>2,5</sup>*

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Hastened death, including assisted suicide and euthanasia, where legal, is governed by laws and policies that determine who can access medication, and medical treatment and support. Yet the ability to hasten one's death is further facilitated or constrained by layers of informal power structures, including social norms and interpersonal and interprofessional dynamics. These dynamics, often undiscussed, affect those seeking to hasten death, their families and caregivers, and the clinical professionals from whom they seek care. In this session we will explore the role of power in hastened death through research in three countries and the implications for practice, policy, and education. Dr. Claudia Gamondi will present results of research on Swiss family members' experiences of patients pursuing assisted suicide in Switzerland. Janette Fish will present results of a qualitative study of UK families of individuals pursuing assisted suicide in Switzerland. Victoria Ali will present results of a systematic review of clinician experiences of inquiries about hastened death dependent on legal status. Dr. Jane Lowers will present findings on a study of caregivers of US patients who hastened death by stopping eating and drinking.

**Abstract ID: 62**

**Abstract Type: Free Communication - Compassionate cities**

### **What constitutes a caring community? – A qualitative study**

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**Background:** International studies have shown that competent health and social care is a prerequisite for the best possible quality of life, especially at the end of life. It is known that in addition to medical factors, socioeconomic and cultural

determinants have a significant influence on health and social care for terminally ill people and their relatives. Health and social care institutions have an important role in promoting compassionate care by raising awareness of death, dying and grief, initiating direct services and strengthening professional and non-professional networks. The project “Caring Community Cologne” seeks to create sustainable structures in an urban area in order to establish a Caring Community within person-centered end-of-life care.

**Methods:** Two audio-recorded focus groups were conducted, with  $n=9$  participants from multi-disciplinary community-based services in the city of Cologne and members of the Caring Community Cologne (e.g. local government, hospice and palliative services, actors from civil society). The recordings were transcribed verbatim and analysed thematically following Clarke and Braun.

**Results:** Participants discussed the characteristics and difficulties of implementing a Caring Community. The following most important factors were derived:

- Support from municipal politics (public administration, health department, mayor) necessary
- Top-down-approach at the beginning of a project to build up basic structures, followed by bottom-up-concepts for community and citizen engagement
- Professional leadership and moderation
- A high degree of interaction and networking between the actors themselves

**Discussion:** Shared values and trust in the common project can be seen as a main prerequisite for initiating a caring community. All of the participants showed an intrinsic motivation for the common goals. Participants discussed that missing components in the local process such as a lack of citizen's participation, transparency of internal and financial structures and a lack of voluntary work hindered the project. In addition, it became apparent that the role of healthcare should not dominate other structures in the project. Based on these results, we currently plan to conduct in-depth expert interviews with professionals who already have experience in building up and implementing community-oriented networks to further explore the identified factors.

**Abstract ID: 63**

**Abstract Type: Free Communication - Equity and Access**

**How does poverty affect attitudes towards dying? Experiences of individuals and professionals in UK low-income communities**

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**Background:** Public health approaches to palliative care and ‘death awareness’ initiatives encourage individuals to prepare in advance for their care and circumstances at end of life. Research shows that people living on a low-income are less likely to access palliative care services and are increasingly likely to experience funeral poverty, however little is known about how poverty affects attitudes towards dying.

**Aims:** This study examines attitudes towards talking about death and preparing for end of life within low-income communities, and the ways in which experiences of poverty at end of life and in bereavement shape attitudes towards dying.

**Methods:** Qualitative interviews were carried out with 14 bereaved individuals with lived experience of poverty at end of life or in bereavement, and 15 professionals supporting individuals in low-income communities (e.g., funeral directors, social workers, advice workers, faith leaders). Interviews were conducted via phone/video call and data include experiences of end of life and bereavement both before and during the pandemic.

**Results:** Data from the interviews showed experiences of poverty and bereavement across the life course affected people's attitudes towards preparing for death and their own end of life care. Issues such as housing insecurity, immediate economic concerns and fear of funeral costs affected people's perceptions of choice and the relevance or accessibility of planning in advance for care or arrangements after death.

**Conclusion:** An increased awareness amongst healthcare and other professionals of what is important to patients and families on a low-income may help them to better support them in

preparing for end of life. A better understanding of the ways in which structural inequalities impact on social and emotional, as well as practical, aspects of dying can also help inform the development of inclusive public health approaches to palliative care that include policy or system level changes as well as addressing individual needs.

**Abstract ID: 64**

**Abstract Type: Free communication - Arts and end of life**

**Play elements in intergenerational arts activities to support engagement with end-of-life issues – Studio DöBra**

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**Background:** End-of-life (EoL) issues can be difficult to talk about and arts activities have been found to offer alternative ways of engaging with them. However, little is known about the mechanisms through which this occurs. In Studio DöBra, a Swedish community-based intergenerational initiative, children (9 y/o) and older adults (most 80+) engaged with EoL-issues through arts activities.

**Aim:** We aim to explore mechanisms in arts activities that support community engagement with EoL-issues, based on Studio DöBra.

**Method:** Through participatory action research with community-partners, two Studio DöBra iterations were developed. Each engaged 8 children and 8 older adults in a series of five 2-hour workshops with various arts activities about EoL-issues. Data includes participant observations and follow-up interviews with community-partners, children, and older adults. Initial analysis conducted with community-partners indicated the importance of play elements in arts activities. Continued analysis was abductive, iteratively moving between play theory and data. We modified theory as we identified mechanisms in arts activities supporting engagement with EoL-issues.

**Results:** We identified 4 mechanisms: 1) A “Studio DöBra magic circle” i.e., the spatial and

temporal boundary separating the Studio DöBra workshops from “ordinary life” that created space for intergenerational engagement with EoL-issues. 2) Partners made efforts to balance restrictions and freedoms in topics and arts processes, to support participants’ independent engagement with EoL-issues, while maintaining a sense of control for themselves. 3) The definite and abstract nature of death was approached through a combination of imagination and sharing personal experiences. 4) Collective arts processes and products contributed to a sense of community which continued after Studio DöBra.

**Conclusion:** Findings can contribute to theory-building that can inform arts activities supporting community engagement with EoL-issues.

**Abstract ID: 65**

**Abstract Type: Free Communication - Community engagement and development**

**Investigating impact development in Studio DöBra, a community-based participatory action research project to strengthen community engagement with end-of-life issues**

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**Background:** There is an increasing body of participatory action research (PAR) using a health promotion approach to strengthen community engagement with end-of-life (EoL) issues. However, the impact of such research and the way it develops is rarely investigated. This may in part be due to the emergent and context-specific nature of PAR, which complicate the understanding of impact development processes.

**Aim:** We investigate impact and the process of impact development in a community-based PAR project, called Studio DöBra.

**Method:** Studio DöBra was a Swedish initiative to engage communities in EoL-issues. It was developed in partnership with a range of community organizations and engaged children (9 years old) and older adults (most 80+) with topics

related to dying, death and loss through arts activities. Qualitative data from interviews and meetings spanning 4.5 years reflects perspectives of community- and academic partners. Through a qualitative framework analysis based on this empirical data, we expand on Banks et al.'s (2017) theory of "co-impact" in PAR, to develop a model of impact development conceptualizing impact as both process and product.

**Results:** This model identifies three types of impact as product: Impact on individual and group development, action-oriented impact, and strategy-oriented impact. The model highlights impact as a process by illustrating ways in which the types of impact evolve from one another, are related, and are affected by contextual influences. Based on this model, we will also present the impact of Studio DöBra from the perspective of partners.

**Conclusion:** Findings contribute to conceptualizations of impact in PAR, particularly in the field of health promotion approaches to strengthen community engagement with EoL-issues. Findings also contribute with a community perspective to the limited literature investigating impact of community-based health promotion initiatives related to EoL-issues.

**Abstract ID: 68**

**Abstract Type: Free Communication - Compassionate cities**

### Living and Dying in the City of Bern – Development and Implementation of the Bernese Charta for a Commonly Supported End of Life

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**Background:** End-of-life care is not only the state or healthcare organizations' responsibility but of the whole population. In the city of Bern, many individuals, companies, cultural organizations,

schools and religious or spiritual institutions, share this vision. This project aimed to bring together these potential partners for reaching optimal impact in the city's population.

**Methods:** A personal initiative of a professor for palliative care at the University of Bern together with the Mayor of the city of Bern in 2018 led to a fireplace conversation with representatives of the city administration, local companies, university, churches, schools and culture. This was followed by a series of public lectures on different topics around the end of life, including a public debate hosting Prof. Allan Kellehaer. A local coordinating group was built in order to elaborate a strategy how to launch the city charter derived from the international model of compassionate cities.

**Results:** The Bern charter for mutual support at the end of life was finally launched in November 2, 2020. Multiple public events were conducted including hearings, workshops and film discussions. Populations' response was overwhelming and clearly showed the need to talk about end of life topics. Various activities have resulted: e.g. students of the Pedagogical School of Bern conceptualized an interdisciplinary project week on the topic of dying and death; a public website [www.baerntreit.ch](http://www.baerntreit.ch) and a yearly public event were established to raise awareness, drive coordination and information including media coverage.

**Conclusion:** With its own Compassionate City Charter, the city of Bern has established a solid basis for current and future projects. Many professionals and volunteers are engaged in various activities; however, permanent effort is needed to keep the movement running including media attention. The broad spectrum of target groups is a chance and a challenge at the same time.

**Abstract ID: 69**

**Abstract Type: Free Communication - Volunteers and compassionate neighbors**

### Service evaluation of compassionate neighbours programme at St Clare Hospice

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**Background:** Compassionate communities as part of the public health approach to end-of-life



care (EoLC) offers the possibility of solving the inequity of the difference in provision of care for those people with incurable cancer and those with non-cancer terminal illnesses. Building networks of support involves across the whole spectrum of society, including workplaces, educational institutions, churches and temples, neighbourhoods, community centres and in health and social care organisations.

Compassionate Neighbours at St Clare Hospice is a volunteer-led project, working to help tackle loneliness and social isolation amongst local people who are living with a life-limiting illness, or who are experiencing frailty due to older age. Compassionate Neighbours (CN) are matched with Community Members (CM-patients) to achieve the outcomes which suit patients. This paper evaluates the usefulness of the programme.

**Methods:** A questionnaire survey was conducted with 10 CNs and 10 CMs. Questions were asked about achieving following goals: Providing information about hospice's work to community, support to community to look after aging/isolated residents, achieving goal of people feeling less alone towards the end of their life, informing CN/CM of choices and services available in health-care towards the end of life and providing CM a connection with community.

**Analysis and Results:** 19/20 respondents were females and 19/20 were over 55 years of age. 11 lived in urban and 8 in rural areas. All 20 had been connected with programme for over 6 months. Following responses were received:

- 17 – Programme informs about hospice's work in community
- 18 – It provided support to community to look after aging/isolated residents
- 19 – It achieves goal of people feeling less alone towards the end of their life
- 14 – It informs CN/CM of choices and services available in healthcare towards the end of life
- 15 – It provides recipient a connection with community

**Conclusion:** Most CN/CM are confident that programme achieves providing information, supporting community and prevents isolation. However, there are minority who still voiced concerns about these goals. Further research is

required to explore community's expectation from this programme and training of CNs accordingly.

**Abstract ID: 70**

**Abstract Type: Free Communication - Loss and grief**

**Therapeutic outcome measure use in an online bereavement counselling service (OBCS)**

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**Background:** Prior to the coronavirus pandemic, there was controversy as to whether online counselling services are as effective as therapy in a counselling room.

To evidence effectiveness and usefulness the bereavement care service standards recommend for services to be set up with assessment and outcome measures.

**Method:** The OBCS therefore set up a pathway to implement these standards: 172 people were assessed using the Adult Attitude to Grief (AAG) scale (Machin, 2014) which determines the presence of overwhelmed feelings and controlled functioning, and the resilient capacity to balance these.

**Results:** The majority (85.4%) reported a decrease (an improvement) in their score, although for some 7.6% the score remained the same before and after. For a small number, 7.0%, the score increased. 69% of those who had reported suicidal ideation prior to counselling responded 'No' after counselling.

People were also assessed using the Detection of Emotional Distress scale (DED). The majority, (82.7%), reported a decrease in their score (improvements), for some the score remained the same (7.9%) before and after. The score increased for 9.4%.

**Conclusion:** Findings suggest that the OBCS is an effective service for most clients. To understand how grief impacts people in today's society, help normalise grief and perhaps challenge the existing focus on formal support, we need to explore the data further to make assumptions about what increases client vulnerability, types of services and community development are required and if the effects are lasting.

**Abstract ID: 71**

**Abstract Type: Poster – Various Topics**

**Patient safety in palliative care: improving system design for safe, responsive medication management**

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Around 20% of serious palliative care safety incidents involve medication. WHO advocates halving this in 2022. Avoidable harms occur if care is not appropriately individualised. This symposium collates four papers to examine palliative medication management. Our objective is to focus system design on improving safe, responsive medication management. We will invite audience reflections and interactive discussion of implications for policy, practice and future research.

1. Integrating sociocultural and safety theory: novel methodological framework
2. We share methodological advances in integrating sociocultural and safety theory, applying the resulting framework to synthesise multi-voiced empirical data. This aids understanding of human factors in system design, illuminating barriers to achieving patients', carers' and healthcare professionals' improvement priorities.
3. Patients' and carers' perspectives of palliative medication safety: scoping review
4. Joanna Briggs Institute methods scoped how patients and carers make sense of medication management. Data were extracted from peer-reviewed and grey literature to understand human factors. Thematic analysis identified what matters most for safety in prescribing, supply, administration, desired/adverse effects, review and disposal.
5. Professional reporting and contributing factors: national incident data
6. Palliative medication-related incidents in the National Reporting and Learning

System, England and Wales were sampled for those resulting in severe harm/death and/or involving continuous subcutaneous infusions. Mixed methods analysis explored contributory factors and professional perceptions of incidents.

7. Experiences of community anticipatory medications: longitudinal qualitative interviews
8. Patients', carers' and clinicians' experiences of injectable anticipatory medications at the end-of-life were investigated. Findings demonstrate the importance of a multi-voiced approach to improve safe and timely medication management.

**Abstract ID: 72**

**Abstract Type: Poster - Various Topics**

**Getting palliative prescription medications right at home, in hospital & hospice: Activity Theory analysis**

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**Background:** The work of medication-related activities to achieve effective symptom control is poorly understood. This study synthesises experiences of patients, carers and professionals to map work in the multi-step processes underlying medication management: decision-making/prescribing; monitoring/supply; use (administration); deprescribing/disposal; transitions (home/hospital/hospice).

**Methods:** Joanna Briggs Institute scoping methods were used to identify relevant literature for creating an initial model of intended processes in prescribing/medication use across home, hospital and hospice. Direct observation of everyday practice, conducting informal conversations around the acts of prescribing and medication use, was undertaken in each setting prior to purposive sampling of patients, carers and professionals for qualitative semi-structured interviews. Data capture was through fieldnotes, audio-recording/transcribing, and pictorial representations. Drawing



on Activity Theory, to understand what happens, who does what, how, when and where, an analysis of multiple perspectives was mapped to the initial model of intended processes, expanding it into a practice-based model.

**Results:** The resulting theoretically-informed, empirically-evidenced model reveals hot (debated) and cold (overlooked) spots; both need system innovation to improve care. Scrutinising prescribing and medication use processes by applying our model may reduce the need for unanticipated care provision and decrease patient/carer burdens. We are also using the model to create supportive resources for professionals, patients and families.

**Conclusion:** Better understanding of processes experienced, as distinct from intended, is a valuable method to identify targets for system change, and new forms of practice. Understanding the effort of work activities required in the effective use of prescription medications, and when disruptions occur, is crucial to designing, testing and implementing improvements.

**Abstract ID: 73**

**Abstract Type: Free Communication - Loss and grief**

### **In-hospital bereavement services as an act of care and a challenge: An integrative review**

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**Background:** In Western countries, people most often die within hospitals. Hence, healthcare providers are often confronted with dying persons and their bereaved relatives. The aim is to investigate current in-hospital bereavement care (operational definition, implementation, relatives' satisfaction, and barriers or facilitators) and the extent of responsibility hospitals carry in offering this.

**Methods:** An integrative review was conducted by searching four electronic databases (PubMed,

Embase, Web of Science, CINAHL), from January 2011 to December 2020, resulting in 47 articles. Different study designs were included and results were reported in accordance with the theoretical framework of Whittemore and Knafl (2005). The quality of all included studies was assessed by using the Mixed Methods Appraisal Tool.

**Results:** Only four articles defined bereavement care: two as services offered solely post loss and the other two as services offered both pre and post loss. Although different bereavement care services were delivered surrounding the time of death, the follow-up of bereaved relatives was less routinely offered. Relatives appreciated all bereavement services, which were rather informally and ad-hoc provided to them. Healthcare providers perceived bereavement care as important, but the provision was challenged by numerous factors (such as insufficient education and time).

**Conclusion:** Current in-hospital bereavement care can be seen as an act of care that is provided ad-hoc, resulting from the good-will of individual staff members. A tiered or stepped approach based on needs is preferred, as it allocates funds towards individuals-at-risk. Effective partnerships between hospitals and the community can be a sustainable and cost-effective strategy.

**Abstract ID: 74**

**Abstract Type: Poster – Various Topics**

### **Reclaiming relationships as a legitimate tool for systems change: A Change Laboratory approach to palliative care**

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**Background:** In the UK, Palliative Care models require consultative, collaborative working between specialist/generalist healthcare professionals (across community and acute hospital services). Patients experience multiple transitions, boundaries and interfaces between locations and providers. We present our experience of Change Laboratory (CL) methods to create a:

- framework for socioculturally-mediated improvement initiatives

- multivoiced understanding of the value of relationships in system change

**Methods:** Our study was co-designed with 11 patients/carers. CL is a formative intervention based on Cultural-Historical-Activity-Theory. Analysis is directed to how what people think/feel relates to what they do. Monthly workshops (Jan-Jul 2022) with patients/carers and professionals are exploring prompts (mirror data) derived from anonymised interviews and acute hospital/community observations ( $n = 148$ ). Creative quality improvement activities help participants question system tensions/gaps, analyse challenges, model new ideas and consider transferability into practice. Audio-recording for transcription, researcher fieldnotes/reflexive notes and task artefacts are fed forward to later sessions and subject to qualitative analysis.

**Results:** The CL method helps move from problems to ideas for future practice. We will present full results with emphasis on expansive learning (creation of new knowledge/practices) as people shared expertise and experience. We are using our analysis to develop a framework for system improvement that integrates: 1. 'relational reach' (bridging work to link people across systems and hold complex situations) and 2. 'relational glue' (support constructed between people, mediated by trust, empowerment and ability judge customised, flexible responses are needed).

**Conclusion:** Our work can be used to design systems that encourage sustainable replication of relationships. This could reduce inequities by creating systems that facilitate relationship-based care.

**Abstract ID: 75**

**Abstract Type: Free Communication - Loss and grief**

### Bereaved relatives' experiences with and expectations of hospital based bereavement care: a qualitative study

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**Objectives:** In Western countries, people most often die within hospitals. Hence, healthcare

providers (HCPs) are often confronted with the care for bereaved relatives. Due to a lack of literature on in-hospital bereavement care, this study aimed to explore relatives' needs and experiences regarding in-hospital bereavement care offered by HCPs.

**Methods:** 16 semi-structured interviews with adult family members bereaved after in-hospital death. Transcripts were analyzed using thematic analysis (Braun & Clarke, 2019).

**Results:** Participants did not perceive bereavement care as restricted to the post loss phase, but also communicated various antemortem needs, which constituted a founding base for continued interactions with HCPs. The pre-loss contacts with in-hospital health care providers formed the point of departure for renewed contact post-loss. Participants preferred HCPs who did not excessively interfered or patronized but were rather present on the background. After the loss, a minority of participants reached out to HCP themselves, but did not expect continuity of support from hospital staff. Nonetheless, several barriers and facilitators were experienced when relatives wanted to contact HCP post loss.

**Conclusion and clinical implications:** These findings illustrate the importance of understanding hospital based bereavement care as services that can be offered both pre and post loss. However, hospitals are not the sole provider and can benefit from collaborations with existing community-based initiatives. As such, hospitals may be better placed to fulfill antemortem needs and screen family members for bereavement-related challenges so they can identify, target and refer groups-at-risk towards adequate support (tiered or stepped model).

**Abstract ID: 76 (& 244)**

**Abstract Type: Workshop**

### Settings of dying – The possibilities and limits of 'designing' at the end of life

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Based on our ongoing research project “Settings of Dying” (sterbesettings.ch/en), in this workshop, we aim to take a close look at the understanding and practice of “gestalten/designing” in end-of-life care settings (e. g. palliative care in hospitals or hospices). We approach “gestalten/designing” from an interdisciplinary perspective that includes social anthropology, nursing, literary studies, communication design, product design, philosophy, sociology of religion, and performative arts to explore the complexities, nuances, and contingencies of contemporary dying in Western European societies and beyond.

Conducting our research in Switzerland, a country that places a high value on individual responsibility, autonomy, and freedom of choice, allows for reflections on the possibilities and limits of “gestalten/designing”, of who is (co)designing for whom and with whom, and the role of caring and compassionate communities at the end of life.

In our research project, we look at a variety of settings to understand how practices, motives, and materialities shape the end of life: from hospitals to hospices, from autobiographical literature to digital spaces. Which images are used to illustrate dying or palliative care? And how could we contribute to the democratization of end-of-life care with the design of new images or products? Which potentials and challenges does palliative care, with its community-focused and family-centered approach, offer for the highly economized and fragmented healthcare system it is situated in? How does digitalization influence contemporary experiences of dying? And how do current literary accounts contribute to broadening our perspective, and vocabulary, of dying today?

Inspired by an interactive workshop format, we plan to have a mix of short presentations of individual research projects, demonstrations of design objects, and readings followed by a moderated

discussion centered around the workshop’s theme.

**Abstract ID: 77**

**Abstract Type: Poster – COVID**

**Elderly Covid -19 patients in nursing home  
cared by young doctors together with Palliative  
Care teams. A model beyond pandemic?**

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**Background:** The Special Units of Continuity of care (USCA in Italian) are one of the effective strategies to fight against the Covid-19 pandemic and to avoid the risk of the downfall of the National Health System: they are medical teams dedicated to the care and follow up of Covid-19 elderly patients who lived in long-term care facilities, to give relief to symptoms and related outcomes, assuring a proper follow-up or appropriate end-of-life care.

**Method:** The main aim of this workshop is to share an experience of the effective collaboration between the Palliative Care Unit of Ravenna and the “USCA” in the management, care and support of patients suffering from Covid-19. Since they have a higher risk of dying or having critical issues, this collaboration included a palliative care approach for informing, supporting, and training doctors serving within USCA and experiencing, for the very first time, end-of-life care needs.

**Results:** We will take advantage, together with presentation of this experience, from presenting the results of a phenomenological qualitative study conducted with doctors working in USCA and nursing homes during the pandemic.

**Conclusion:** We shall illustrate a narration of collaboration and comprehensive service whose primary outcome was to fill the potential gaps among actual needs, availability to the “right care in the right moment,” through the implementation of a palliative approach model that could help patients, families, and professionals not only in the dramatic scenario of the pandemic.

**Abstract ID: 81**

**Abstract Type: Free Communication - Volunteers and compassionate neighbors**

**Compassionate neighbours at hospices: where are we? A survey of selected service managers**

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**Background:** In the last decade, there has been an evolution of organisations that help construct Community-Based Palliative Care programmes like Compassionate neighbours. However, there is variation in delivery methods of these programmes.

Compassionate Neighbours at St Clare Hospice is a volunteer-led project, working to help tackle loneliness and social isolation amongst local people who are living with a life-limiting illness, or who are experiencing frailty due to older age. Compassionate Neighbours (CN) are matched with patients to achieve the outcomes which suit patients. While we continue to develop our service, we conducted a survey to explore models on CN service from 7 different services.

**Methods:** A telephonic structured survey was conducted with 8 responsible personal of CN programmes. Questions were asked about:

- Hospice's relationship with community
- Awareness of service known by healthcare professionals and by community
- Most important achievements of service
- If service to be launched, what would you do differently?

**Analysis and Results:** 5/8 respondents were females and all 7 services had different titles for their lead. Services had been run for 3 – 7 years (mean 4 years) in London or surrounding counties.

All 8 respondents felt that it had improved relationship with community. At a score of 0 – 5, mean score was 3 for awareness among professionals and 2 for awareness in community.

There were multiple themes about achievements including breaking through isolation, working partnerships, thriving in pandemic and raising

profile of psych-social support. Among new things to do, themes included robust planning, exploring local needs and collecting data first. Moving forward, themes included renaming the service, change from outputs to outcomes and regular evaluation. Detailed themes to be presented at conference.

**Conclusion:** CN projects vary according to local needs. Despite a growing level of satisfaction among managers, there was understanding that there could be other paths taken to improve or restart service. Developing an individually tailored package of care appears to be able to meet specific needs.

**Abstract ID: 82**

**Abstract Type: Poster - COVID**

**Variation in palliative care service response and association with Covid-19 mortality rates: an ecological study in UK regions**

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**Background:** The Covid-19 pandemic has caused a huge impact on palliative care services. Results from a nationwide survey of palliative care services in the UK (CovPall survey) show services experienced an increase in their workload and were forced to implement changes to cope with these challenges. We aimed to examine the relationship between mortality during the first wave of the Covid-19 pandemic and regional variation in palliative care service response.

**Methods:** Ecological study using mortality data from England, Wales, Scotland and Northern Ireland, linked with results from CovPall survey. Age and sex standardised mortality rates for Covid-19 between 1st March and 31st July 2020, and the proportion of hospice and palliative care services reporting being 'more busy' than before the Covid-19 pandemic were calculated at Nomenclature of Territorial Units for Statistics (NUTS) level 1. A Pearson correlation was calculated between the standardised covid mortality



rates and the proportion of services being 'more busy'. Results were stratified by service setting and funding.

**Results:** Of 263 UK survey responses, 50.20% of services reported being 'more busy' during the first wave of Covid-19 Pandemic. London was the region with a higher proportion of services referring to being 'more busy' than before the pandemic (70.73%) and also with the highest standardised covid mortality rate of (SMR) 14.88 per 10000. Regions with higher Covid mortality rates tended to be more likely to have a higher proportion of services referring to being busier in that period. This trend was more evident for services providing care in the community and was statistically significant for services with more than 25% of their funding coming from the National Health Service ( $\beta$  0.54, p-value 0.049).

**Conclusions:** The funding model for hospice and pall care services may influence their ability to respond to sudden increases in demand. More research is needed to understand to what extent community palliative care services were more affected than hospital-based services by the pandemic in terms of workload.

**Abstract ID: 83**

**Abstract Type: Poster - Family caregivers**

### **Conversations and care at end-of-life for persons with dementia: Family care partners share their perspectives**

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**Background:** End of life care planning for individuals living with Alzheimer's disease or a related dementia (ADRD) is lacking.

**Purpose:** The purpose of this study was to explore the end of life experience for persons living with Alzheimer's disease or related dementia (ADRD) and who died in the past 12 months; specifically the care received and conversations around end of life as perceived by a family or close other caregiver.

**Methods:** A quantitative survey and qualitative interview guide was developed based on findings from the literature. Participants were recruited

through community outreach, grief groups, and social media. Participants were invited if they experienced the death of a close loved one within the previous 12-months and whose loved one was diagnosed with ADRD. N = 8 individuals, who identified as a close caregiver of such a loved one, agreed to participate, completed the survey via Qualtrics, and participated in an interview.

**Results:** Findings will be reported including quantitative findings, and themes encompassing the kinds of end of life care desired and received as well as experiences with end-of-life care planning prior to the loved-one's death.

**Conclusions:** Findings from this study will inform end-of-life care and planning for individuals living with ADRD.

**Abstract ID: 85**

**Abstract Type: Free Communication - COVID-19**

### **Fear of death and coping strategies of healthcare professionals during the COVID-19 pandemic**

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**Background:** The death of a patient is a traumatic event for health care professionals (HCP) that triggers feelings of sadness, guilt and anxiety. A pandemic context characterised by high rates of death and extremely increased demands to the Health System (HS) should affect the coping abilities and perceived fear of death of the HCP. In this research we profile the coping strategies and fear of death of HCP in Andalusia during the emergence of the third wave of the COVID-19 pandemic.

**Aim:** This study aims to depict the coping with death abilities and fear of death perception in different levels of the HCS.

**Methods:** This research took place during the so-called 3rd wave of the COVID-19 pandemic in Spain. HCP from different healthcare levels (HCL) in Andalusia (south of Spain) self-respond online and anonymously to the Collet-Lester (Coping with death scale) and Bugen (Fear of death) questionnaires.

**Results:** 382 questionnaire answers from HCP were analysed. Majority of respondents were women (69.1%), under 30 y.o. (20.4%), married (73%), religious (48.3%), with more than 20 years of experience (45.5%), most had experience with dying patients (95.5%), lost a loved one (45.8%) and experienced the serious illness of a close relative (45.5%). Distribution of HCP was 57.9% Primary vs. 41.4% Secondary HCL.

Moderate perception of fear of death was observed, being lowest when it had to do with their own death (mean = 2.950; SD = 0.899) and highest related to their own death process (mean = 3.646; SD = 0.736). With respect to the coping strategies, the HCP showed also a low-moderate perception (mean = 140.008; SD = 22.641) of their abilities and resources dealing with the dying. There were no differences in such values attending to the health care level ( $p > 0.005$ ).

**Conclusion:** Likely due to the increased stress to the HS during the pandemic, HCPs present a moderate-high degree of fear of death and acknowledge having a moderate-low level of competency in caring for people at the end of life.

**Abstract ID: 88**

**Abstract Type: Poster - Literacy & Education**

### **A Systematic Scoping Review on Moral Distress in Undergraduate Medical Students**

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**Background:** Current concepts of Moral Distress (MD) highlight the complex yet person-alised concept amongst healthcare professionals. Yet, medical students can also be victims of MD. Amidst a dearth of data suggesting that MD stems from conflicts between deep beliefs, principles, values, prevailing roles, expectations and responsibilities, a systematic scoping review (SSR) is proposed to evaluate what is currently known about MD and how it arises through the Ring Theory of Personhood (RtoP). The RtoP encapsulates the intricate relationships of personhood while factoring in situational, environmental and/or relational sources of conflict. Data obtained from multiple settings and various research methodologies would enhance understanding and guide the provision of better support for medical students in tackling MD by identifying the various sources of tension in medical students.

**Methods:** An SSR adopts the Systematic Evidenced Based Approach (SEBA) to map prevailing accounts of MD in medical students. To enhance the transparency and reproducibility of this process, concurrent and independent use of tabulated summaries, thematic analysis and directed content analysis (Split Approach) is adopted.

**Results:** 28,070 abstracts were identified from eight databases, 314 articles were reviewed, and 19 articles were included. The Split Approach identified four domains including definition of MD, sources of MD using RtoP, recognition of MD and interventions.

**Conclusion:** This SSR suggests current concepts of MD have extended beyond Jameton's definition of MD and that disharmony and/or dyssynchrony between each ring of RtoP requires a personalised and longitudinal approach to accurately evaluate MD in medical students. Through the use of RtoP which can evaluate MD holistically, further research into the design of a RtoP based tool can be used to assess MD and its long-term impacts. The active role of medical schools in resolving MD in medical students remains imperative and requires a multi-faceted framework to target key causes. We are hopeful that MD in medical students can be better managed



through the provision of personalized, appropriate, and holistic support to medical students.

**Abstract ID: 90**

**Abstract Type: Poster – COVID**

**Opportunities and challenges to family carers end of life care research in the COVID pandemic: A researcher's reflections**

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End of life care research provides significant input and direction for improving end of life care services for patients and their family carers. However, various challenges could be experienced regarding participants access and ethical concerns that appear while designing and conducting the study. Careful planning and adaptation to the emerging challenges should support the successful attainment of the recruitment targets while maintaining ethical standards. The COVID pandemic has significantly impacted accessing and maintaining contact with potential research participants. This paper reports on challenges and opportunities experienced as a novice PhD researcher during the global pandemic. The qualitative study explored experiences of family carers of people with cancer receiving home-based-end of life care. By working iteratively and innovatively strategies were implemented to overcome this unexpected dilemma. Getting the research sites involved in the study during the pandemic was a massive challenge due to the redeployment of medical research staff to support COVID containing efforts. However, keeping regular contact with participating sites while being open to new sites helped to revive the study activities. Finding ways to nationalise the study were thought helpful such as using the National Institute for Health Research (NIHR) support and online recruitment that extended the recruitment limits. Conducting research remotely was a valuable opportunity that aligned with the “Work from home” strategy to contain the pandemic. It saved travel time and allowed greater flexibility for family carers to participate in the study. However, it involved various ethical issues regarding consenting and maintaining participants’ confidentiality and emotional safety. However, engaging the

participants and giving them control over their involvement were significant facilitators for participant retention in the study. Flexibility and resilience while conducting research is important to overcome unprecedented circumstances. The strategies used in the current study were successful in recruiting a sample size sufficient to achieve qualitative data saturation. This may provide insight and guidance for other researchers in similar situations.

**Abstract ID: 91**

**Abstract Type: Symposium**

**Empowering family carers to support people requiring palliative care**

*Peter Hudson\*<sup>1,3</sup>, Clare Gardiner<sup>2</sup>, Aline De Vleminck<sup>3</sup>, Sigrid Dierickx<sup>3</sup>*

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**Background:** Palliative care aims to enhance the quality of life of people living with serious and life-limiting illness and their family carers. However, despite policy, clinical and research evidence underpinning the importance of a family approach to palliative care challenges have impeded optimal support. Furthermore, much of the scientific focus has tended to target patients’ needs with less attention given to family carers.

**Purpose:** Provide a summary of the status of the international evidence regarding family carer support and an overview of select initiatives focussed on carer empowerment.

**Method:** A symposium facilitated by the Chair and Co-chair of the management committee of the European Association for Palliative Care’s Reference group on family carers

(<https://www.eapcnet.eu/eapc-groups/reference/family-carers/>) which will include presentations on:

- (1) Brief overview of status of evidence regarding carer support and the role of the EAPC family carer reference group (Peter Hudson, Australia)
- (2) Economic impacts for family carers : End of life caregiving and paid employment (Clare Gardiner, England)

- (3) Empowering family carers via the support of and collaborations with health professionals (Aline De Vleminck, Belgium)
- (4) Family carers' support needs throughout and after the euthanasia procedure (Sigrid Dierickx, Belgium)

**Outcomes:** Participants will be informed about contemporary international evidence regarding the status of support for family carers of people requiring palliative care. They will also be provided with examples of initiatives that promote carer wellbeing as well as resources that target family carer empowerment. There will be dedicated time allocated to audience discussion so that further insights and strategies for carer support can be shared.

**Abstract ID: 92**

**Abstract Type: Free Communication - Community ACP**

### **The cultural adaptation of the GoWish cards for use in Flanders, Belgium: a game to identify and discuss end-of-life preferences**

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**Background:** Games like the GoWish cards, from the US, have been found useful to support people in reflecting about their end-of-life preferences. Because card games like GoWish are culturally sensitive, we aimed to perform a systematic cultural adaptation of the cards for use in Flanders, Belgium involving multiple stakeholders.

**Methods:** We used an iterative cultural adaptation process with repeated discussions with various community organizations and representatives of minority and religious groups. Next, the cards were evaluated in relation to: linguistic equivalence to original version, applicability, comprehensibility, and relevance per card. Based on the evaluation for each item the content validity index (I-CVI) was calculated with >0,78 as minimum required score. The translated version was tested with potential users. Their feedback and items with a I-CVI of <0,78 were used for final adjustments.

**Results:** After translation, the organizations and representatives of minorities and religions made cultural adaptations to nine cards (e.g. "accomplishments" was changed to "memories" since this was deemed more appropriate in our culture). Because of the legal context in Belgium, two cards were added: "a self-chosen end of life" and "being able to record my choices". The modified version was reviewed by 12 healthcare workers. 28/38 cards had an I-CVI score >0.78 on all four items. Potential users ( $n = 33$ ) felt that the cards supported conversations about end-of-life preferences. Based on the ten cards with a I-CVI <0.78 and feedback from potential users, the wording of four cards was reformulated.

**Conclusion:** Using a systematic process of cultural adaptation involving multiple stakeholders, we were able to identify detailed adjustments needed to achieve cultural adaptations appropriate for use of the cards in Flanders. The strength of the adaptation process lies in the multiple perspectives using different methods throughout the process.

**Abstract ID: 93**

**Abstract Type: Poster - Various Topics**

### **Home-based palliative care and re-hospitalizations for palliative care patients**

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**Background:** Palliative care recipients are more likely to be hospitalized if they do not receive recommended care at home or provided care is not sufficient. Therefore, an overall goal of home-based care for persons with life-threatening diagnoses is to enable End of life support, symptomatic treatment, and risk-prediction - without necessary hospital visits or stationary care. For that reason, It is hugely important to look at a patient's diagnosis to understand better particular diseases that correlate with hospitalization rates.

**Methods:** Hospitalization levels of persons ( $N = 115$ ) receiving home-based palliative care were tracked using an official home care count database. The research explored the International Classification of Diseases (ICD) among palliative care recipients at home and the most common

ICD's of hospitalized patients. The results were grouped by certain ICD's and hospitalization intensity rates. There were reported 43 cases of Homecare recipients referred to hospital health care services.

**Results:** Thirty-eight unique cases, including three persons, were referred two times and one with three referrals. Research revealed that the dominant group (N = 16) had worsened conditions caused by malignant neoplasms (C00-C97), while the second dominant group (N = 6) had a disease related to the circulatory system (I00-I99), followed by the third group (N = 4) of the digestive system disease (K00-K93). Two persons were hospitalized due to bacterial infections.

**Conclusion:** It is notable that 33,0 % of all patients receiving palliative services at their home had to be hospitalized at least one time during last year. The prevalent factor of hospital referral was worsened condition for cancer patients 37,2 %, patients suffering from heart and circulatory system 13,9 % and digestive system 9,3 % diseases. All together, these three groups represent 60 % of all hospitalizations. Further analysis should identify if increased care measures could prevent patients from hospitalization.

**Abstract ID: 95**

**Abstract Type: Poster – Health Promotion**

### **A framework for developing co-designed integrated service model of palliative care for people living with severe mental illness**

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**Background:** Although close to one billion people are living with a mental health disorder globally, it is one of the most neglected areas in Public Health. People with severe mental illness have greater mortality risk than the general population and experience health care inequalities throughout life. There is currently a dearth of evidence in relation to understanding the palliative care needs of people with severe mental illness and how future care delivery can be designed to both recognise and respond to those needs. Historically this has been overlooked in the service model development strategies internationally. This is reflective of

a “loud silence”, and neglect, when it comes to severe mental illness and death and dying.

**Methods:** We have developed a co-design framework that includes six phases. An expert reference group will be established in Phase 1, to inform all stages. Phase 2 a systematic literature review to synthesise current evidence in relation to palliative care service provision for people with severe mental illness. In Phase 3, consultation with both, patients who have a severe mental illness and in receipt of palliative care and bereaved caregivers of people who have died 6–18 months previously with a diagnosis of severe mental illness across two recruitment sites in the United Kingdom. Consultation with both mental health and palliative care multidisciplinary staff in Phase 4. Phase 5 will involve the co-design of a service model of integrated palliative care for persons living with severe mental illness. Phase 6 will develop service planning recommendations for this client group

**Results:** Guidelines for developing a co-designed service model of integrated palliative care will be presented, including steps for enhancing collaboration with key stakeholders within the expert reference group.

**Conclusion:** This framework will significantly address health inequalities for people with severe mental illness via a co-designed approach drawing on the experiences of people with severe mental illness, their bereaved caregivers and health care professionals. An integrated service model is imperative to address the inequity in palliative care provision for people living with severe mental illness, and an important step in promoting inclusion and equality of palliative care provision that is proportionate to the rest of the world's population.

**Abstract ID: 97**

**Abstract Type: Poster – COVID**

### **Experiencing and making sense of illness in an inpatient specialist palliative care unit during a pandemic: an interview study**

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**Background:** In the context of life-threatening illness, sense-making can be described as a process of existential and experiential learning that patients and informal caregivers (ICGs) undergo to cope with an altered life situation. To date, there are no previous studies that have examined patient and ICG sense-making in the inpatient specialist palliative care (SPC) setting. Our aim was to contribute to this gap and investigate the impacts of the COVID-19 pandemic using interviews.

**Methods:** Adult, English-speaking patients and ICGs (non-bereaved and bereaved) participated in virtual semi-structured interviews on an inpatient SPC unit in Ottawa, Canada. Recruitment was limited by the pandemic. Themes were identified using inductive thematic analysis.

**Results:** Three patients (mean age 60.3 years) and four ICGs (mean age 65.5 years) were interviewed. Three overarching themes were identified: i) the journey of dealing with life-threatening illness, ii) impacts of the COVID-19 pandemic on experiences of illness and care, and iii) attempts to cope and find peace. Patients and ICGs perceived receiving high-quality care, but reported divergent experiences of person-centred care in their illness journeys. Pandemic-related visitation restrictions and isolation periods were described as distressing. Coping with the illness and end-of-life journey was a complex part of the sense-making process and was facilitated by a lack of fear of death, support from family members, and religious beliefs. Obstacles to coping and sense-making included family conflict and feeling overwhelmed.

**Conclusion:** Given that inpatient SPC settings involve a significant change in environment and provide care for a limited time, it is important to understand how patients and ICGs experience and make sense of illness and care in such contexts. These challenges call for interprofessional team members to understand and act appropriately in providing care and addressing patient and ICG needs.

**Abstract ID:** 98

**Abstract Type:** Free Communication - Community engagement and development

**An evaluation of asset-based community development (ABCD) in a Scottish Hospice**

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**Background:** Traditionally, Hospices have found challenges when engaging with communities due to fear and taboo associated with death. Professionalisation of death has led to communities losing confidence in their ability to support each other to live and die well.

In 2019, a Scottish Hospice became a Nurture Development Learning Site with the aim of deepening understanding of ABCD, and applying the principles and practices to three distinct communities.

A participatory internal evaluation of the difference this has made both within the organisation and in the communities where this approach has been tested was carried out

**Methods:** A mixed methods approach was used. This included: Developmental Evaluation; Realist Evaluation and Most Significant Change (MSC) technique, in fluid combination. Data was collected from 18 ABCD surveys, six written interview responses, seven key people interviews and two team workshops.

**Results:** Shift was noted at the level of the organisation and communities;

Organisational level:

- from predominantly medical model to a balance of medical and social models
- from doing things to or for people to doing things with people or supporting them to do by themselves
- from identifying needs to identifying what matters most to the person

Community level:

- from focus on health problems to focus on well being
- from reliance on professionals to discovery of community strength and capacity
- from power held by professionals to power held by individuals and communities

**Conclusions:** Coming to understand the irreplaceable role that communities play in supporting End of Life Care marks a coming of age for the Hospice.

ABCD principles and practice have provided a framework for the hospice to deepen its connections



with the local community whilst defining what it can and should contribute as an institution.

By discovering the strengths and resources which exist in abundance in communities the hospice has been able to connect and mobilise these resources to support communities to be places where people who are ageing dying and grieving can live meaningful and valuable lives right to the end.

**Abstract ID: 99**

**Abstract Type: Workshop**

### **Developing compassionate cities and communities: Impacts of a top-down initiation**

*Bert Quintiens\*<sup>1</sup> (chair), Émilie Lessard<sup>2</sup> (speaker), Alison Bunce<sup>3</sup> (speaker)*

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**Background:** Compassionate cities and communities aim to increase capacity around serious illness, death, dying and bereavement through a series of actions aimed at early intervention and prevention on different sectors in society. When initiating such initiative top down, one needs to look for and find motivated people willing to develop the compassionate initiative. This often starts with the recruitment of stakeholders or other partners and appointing a project lead. The partners'/stakeholders' reasons for participating are diverse. They can be recruited through their organisation and then their participation is usually part of their functioning within these organisations. Developing a compassionate city/community is a slow process which aims for cultural and societal changes. Sustainability is key to keep it going on the long run.

**Objective:** The objective of this workshop will be to collect hands-on experience from compassionate city/community developers. To learn from and exchange bilateral experiences and use this to inspire the development of the Flemish compassionate cities.

- What assets/strategies are essential in the top-down initiation of a compassionate city/community?
- How do you keep stakeholders/partners that are involved motivated throughout the project?

- How do you plan for sustainability? If the compassionate city/community incorporates a research component, how do you plan for the time after the research component has ended?

**Speakers:** Three speakers share personal experiences about developing a compassionate city/community with a focus on the objectives above:

- Bert Quintiens (Compassionate Bruges)
- Alison Bunce (Compassionate Inverclyde)
- Émilie Lessard + colleague (Compassionate Montreal)

**Workshop format:** 3 compassionate city/community developers share their experiences in developing compassionate cities/communities. Each speaker talks for about 10 minutes. International experts will be invited to attend the workshop and interactively share.

**Abstract ID: 100**

**Abstract Type: Free Communication - Health Promoting Palliative Care**

### **Understanding early intervention strategies using the 'New Essentials' framework: turning theory into practice**

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Early intervention is a key approach to preventing harm from the known health and social impacts of dying, death, grief and caregiving. It is made up of conscious, planned and deliberate actions. Using the 'New Essentials' framework enables public health practitioners to target interventions to the person receiving care, their caregivers and social networks; communities; civic societies; and health and social services. In this presentation, this framework will be applied to explore early intervention strategies, demonstrate how the Ottawa Charter's five action areas for health promotion are addressed through its use, and provide a rigorous approach to public health practice. Attendees will have the opportunity to identify specific early interventions to apply to their design of Compassionate Communities.



**Abstract ID: 101**

**Abstract Type: Poster – ACP & End of Life communication**

**Idiolectic Conversation and Symptom Management in Palliative Care Patients**

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**Background:** Palliative care contexts require special communication skills on the part of the care team. In the scientific literature, various communication strategies are discussed, which, however, show considerable weaknesses in practice. The shortcomings of traditional methods can be remedied with the help of idiolectic conversation. In “Idiolectics - Eigensprache-orientierte Gesprächsführung und Palliativmedizin”, it is described how this technique can be used in palliative care.

**Objective:** The intention of this pilot project is to demonstrate how idiolectic conversation can be used to activate the psychological and physical resources of palliative care patients, using their own language, as well as to alleviate symptoms, support their decision-making and improve their quality of life.

**Method:** The effect of idiolectic conversation (intervention), is experimentally investigated in the symptom management of inpatients in palliative care, through the instrument Edmonton Symptom Assessment System - ESAS (pre- and post-measurement) idiolectically. In this pilot project, pain, dyspnoea and nausea are initially considered as targets. In order to check for possible positive bias, a standardised, individual interview with the idiolectic interview guide will also be conducted with 10% of the patients.

**Results:** With idiolectic conversation and mindful, respectful interaction with the patient, a possibility opens up for him to better deal with and deal with his often hopeless situation. This also applies to conversations with relatives. With this pilot project, we want to demonstrate that the activation of one's own psychological and physical resources can happen through Idiolectic Conversation Guidance, thereby alleviating the symptoms of palliative care patients, supporting their decision-making and improving their quality of life.

**Conclusion:** With positive results, this communication methodology can lead to the care of palliative care patients as well as activation of their own potential, own resources and thus alleviation of psychological and mental symptoms of the patients. This also serves to support their decisions and improve their quality of life.

**Abstract ID: 102**

**Abstract Type: Free Communication - Equity and Access**

**Housing as a determinant of dying well: Insights from bereaved individuals and professionals in UK low-income communities**

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**Background:** Housing status is one of the key social determinants of health, affecting wellbeing across the life course. However, beyond a recognition that quality of housing quality is linked to place of death, little is known about the ways in which housing quality and security impacts social, emotional, and practical aspects of dying and bereavement.

**Method:** Qualitative interviews were carried out with 14 bereaved individuals with lived experience of poverty at end of life or in bereavement, and 15 professionals supporting individuals in low-income communities (e.g., funeral directors, social workers, advice workers, faith leaders). Interviews were conducted via phone/video call and data include experiences of end of life and bereavement both before and during the pandemic. Transcripts were examined using thematic analysis.

**Results:** Housing emerged as an important factor affecting people's experiences, with seven of the 14 bereaved individuals and all except one of the professionals discussing housing-related issues. Participants described ways in which unsuitable housing and housing insecurity impacted practical aspects of dying such as place of death, and also affected emotional and social wellbeing at end of life. Housing-related issues affected both patients and their families, though families found it difficult to air these concerns when their relative was dying. In some examples professionals taking on an advocacy role were able to support families to address the issues.

**Conclusion:** The data provides evidence of the nuanced ways in which housing issues impact experiences at end of life. A greater awareness of their potential impact could help professionals across sectors, including healthcare practitioners and housing providers, to better support patients and address these issues at an earlier and therefore more effective stage. The data also suggests that housing should be recognised as an important element within public health approaches to palliative care.

**Abstract ID: 103**

**Abstract Type: Free Communication - Equity and Access**

### **Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021**

*Eric Finkelstein<sup>1</sup>, Afsan Bhadelia<sup>2</sup>, Cynthia Goh<sup>3</sup>, Drishti Baid<sup>4</sup>, Ratna Singh<sup>5</sup>, Sushma Bhatnagar<sup>6</sup>, Stephen Connor<sup>\*7</sup>*

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**Background:** Few efforts have attempted to quantify how well countries deliver end-of-life (EOL) care. The objective of this study was to score, grade, and rank countries (and Hong Kong and Taiwan) on the quality of EOL care based on assessments from country experts using a novel preference-based scoring algorithm.

**Methods:** We fielded a survey to country experts around the world, asking them to assess the performance of their country on 13 key indicators of EOL care. Results were combined with preference weights from caregiver-proxies of recently deceased patients to generate a preference-weighted summary score. The scores were then converted to grades (from A–F) and a ranking was created for all included countries.

**Results:** The final sample included responses from 181 experts representing 81 countries with 2 or more experts reporting. The 6 countries who received the highest assessment scores and a

grade of A were United Kingdom, Ireland, Taiwan, Australia, Republic of Korea, and Costa Rica. Only Costa Rica (upper middle) is not a high-income country. Not until Uganda (ranked 31st) does a low-income country appear on the ranking. Based on the assessment scores, twenty-one countries received a failing grade, with only two – Czech Republic (66th), and Portugal (75th) – being high income countries.

**Conclusion:** This study provides an example of how a preference-based scoring algorithm and input from key stakeholders can be used to assess EOL health system performance. Results highlight the large disparities in assessments of the quality of EOL care across countries, and especially between the highest income countries and others.

**Abstract ID: 105**

**Abstract Type: Free Communication - Equity and Access**

### **Winners and losers in palliative care service delivery: Time for a public health approach to palliative and end of life care**

*Samar Aoun<sup>\*1,2,3</sup>, Robyn Richmond<sup>2</sup>, Leanne Jiang<sup>2</sup>, Bruce Rumbold<sup>3</sup>*

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**Background:** Consumer experience of palliative care has been inconsistently and selectively investigated.

**Methods:** People in Western Australia who have experienced a life limiting illness in the past five years were recruited via social media and care organisations (2020) and invited to complete a cross sectional consumer survey on their experiences of the care they received.

**Results:** 353 bereaved carers, current carers and patients responded. The winners, those who received the best quality end-of-life care, were those who were aware of palliative care as an end-of-life care (EOLC) option, qualified for admission to and were able to access a specialist palliative care program, and with mainly a cancer diagnosis. The losers, those who received end-of-life care that was adequate rather than best practice, were those who were unaware of palliative care as an EOLC option or did not qualify for or were unable to access specialist palliative care

and had mainly a non-cancer diagnosis. Both groups were well supported throughout their illness by family and a wider social network. However, their family carers were not adequately supported by health services during caregiving and bereavement.

**Conclusions:** A public health approach to palliative and end of life care is proposed to integrate tertiary, primary and community services through active consumer engagement in the design and delivery of care. Therefore, suggested strategies may also have relevance in many other international settings.

### Funding

Research funded by WA Health.

**Abstract ID: 106**

**Abstract Type: Free Communication: Volunteers and compassionate neighbors**

### Impact of Compassionate Connectors program in Western Australia: Feedback from families, volunteer connectors and services

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**Background:** The Compassionate Connectors pilot program is a partnership between the South West Compassionate Communities Network in Western Australia and the Health Service. It is about a compassionate community model of care where community volunteers provide practical and social support to people with advance life limiting illnesses/palliative care needs.

**Aims:** To identify the impact of the program on access to formal services; community links; social activity; social isolation and coping with daily activities. It also elicited the perceived benefits and challenges as experienced by patients and/or family carers, volunteer connectors and referring service providers

**Methods:** Qualitative evaluation of the impact involved semi-structured recorded phone interviews with the three target groups following a 12-week intervention. Content analysis was used.

**Results:** Twelve connectors worked with 50 families for two years. Without exception, families reported

positive feedback about their experiences with the largest impacts in increasing community links, increasing social activity, and reducing social isolation. The connectors felt the experience was personally rewarding for them to be able to make a difference and see the improvement in people's quality of life. Service providers reported on their increased capacity to offer additional services where formal services were not available, particularly in remote/rural areas. They appreciated that connectors went over and beyond what was expected of this role.

**Conclusions:** This pilot program has demonstrated a successful partnership between formal and informal networks to foster a compassionate community approach to care. The program has been adopted into the practice of the health service as business as usual, with interest for the program to be replicated in several communities.

**Abstract ID: 107**

**Abstract Type: Free Communication - Community engagement and development**

### Democratizing palliative care using a community-based compassionate palliative care model, COMPASS Ghana

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The practice of family caregivers providing care for their loved ones with palliative care needs at home, unsupported by health staff, is common in most resource-poor settings. This practice has implications for the quality of care provided, caregiver stress, the dignity of the patients and, care outcomes as the caregivers use trial and error and bear the entire cost of care.

Despite these challenges, the care provided within the community is the most pragmatic, at least in the short and medium-term, as there are a lack of or inadequate in-patient palliative care units for managing the care compared to most Westernised contexts. The use of context-specific, socio-culturally sensitive approaches, local resources, and expertise offer hope in dealing with the problem.

Compassionate Palliative Services (COMPASS Ghana), a two-arm charity registered in the UK and Ghana, seeks to fill this service gap by enabling access to compassionate palliative and end of life care in partnership with the community leveraging

on the social support. Using a compassionate community approach and the unique socio-cultural African context, COMPASS Ghana revolves around patients' and caregivers' active involvement and participation in care provision. COMPASS Ghana thus offers the most democratic model to deliver palliative and end of life care.

COMPASS Ghana has had solid community and stakeholder engagements and collaboration. In-country needs assessment visits done. The UK arm is focused on fundraising, education, research, advocacy, clinical secondment and fiduciary governance. Ghana arm, the operational arm, will deliver clinical support, training, education, advocacy, technical reach and operational coordination.

COMPASS Ghana's public health palliative care strategy is 'democratic', 'empowering', and 'context-specific' and brings palliative care to people's doorstep. The approach contributes to WHO's recommendation of integrating palliative care as part of universal health coverage.

**Abstract ID: 112**

**Abstract Type: Free Communication - Volunteers and compassionate neighbors**

**Volunteer befrienders supporting people at end of life and their carers at home within a compassionate communities' approach**

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**Objective:** Present research findings to extend the knowledge of volunteer befrienders within a compassionate communities' approach.

Compassionate communities as a public health approach to palliative and end of life care, is being adopted by palliative care providers. Although, volunteers have always been active within the palliative care settings, there is limited evidence of the role of volunteer befrienders as part of compassionate communities. This original empirical research study explores and extends the understanding of volunteer befrienders as part of compassionate communities' approaches in the UK. A qualitative case-study design across three different research sites providing palliative care services, two are hospices and one is a community

organisation. The main data collection methods include semi-structured interviews and focus groups exploring the perspective of: people living with a life limiting condition at end life (primary participants), their family members, and members of the palliative care services. The formal provision of volunteer befrienders was developed as part of a compassionate communities' approach towards the end of life in all three sites. The boundaries of the role varied at each of the sites and the volunteer befrienders experienced the boundaries differently, dependent on the circumstances of the people they supported. The befriender role was fluid as they negotiated the different situation they encountered in their volunteering. It was a unique role that occupied the intermediate sphere of care within the home setting. The data has highlighted an emotional aspect to the role, where volunteer befrienders had to be alert and responsive to the different emotions of the people they were supporting. The literature on emotional labour focuses on professional carers in end-of-life care but there is a lack of literature relating emotional labour in volunteers. It could be argued here that befrienders in end-of-life care may also experience emotional labour as part of their role. The volunteer befrienders formed part of the inner circles of care of people at end of life and their household. This research found the extended role of volunteer befrienders as part of the formal health care provision in the home to be a key attribute of a compassionate communities' approach.

**Abstract ID: 113**

**Abstract Type: Free Communication - Compassionate communities research**

**A compassionate community is a dementia-inclusive community: creating connections using Appreciative Inquiry methods**

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Dementia is a leading cause of death in Australia and its diagnosis brings great fear and distress for many people and their families. Yet it is the connections within communities that can enable the people living with dementia, their families and carers, to remain at home for as long as possible, including until death. Communities where people living with dementia are supported to live with



meaning, purpose and value are dementia-inclusive communities, founded in compassion.

A Compassionate Communities approach was used to build a dementia-inclusive community in the Redlands Coast district near Brisbane, Australia. Previous attempts to create a tangible plan had not succeeded. A group of community members, people living with dementia and their carers, community service providers, local government representatives, funeral directors and aged care providers gathered to identify ways to build a compassionate, dementia-inclusive community. Using Appreciative Inquiry methods, a workshop was held to engage in meaningful storytelling to listen and be heard, identify key themes and create a vision statement for their community.

This process enabled the community itself to articulate their collective intention to educate themselves about dementia; engage young people, local shops and businesses to become 'dementia friends'; support the use of companion animals; increase social awareness and acceptance of dementia; promote dignity and respect; and recognise people living with dementia and their carers as valued members of the Redlands Coast community.

It was very clear in this process that a compassionate community is a dementia-inclusive community. This presentation explains the use of Appreciative Inquiry methods to explore a Compassionate Communities approach to creating dementia-inclusive communities.

**Abstract ID: 114**

**Abstract Type: Free Communication - Community ACP**

**Development and evaluation of a public course in order to empower lay people in the process of advance care planning**

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**Background:** According to the 2017 Swiss Palliative Care Population Survey, the majority of respondents reflect on their wishes concerning their own end of life. However, they express support needs how to proceed towards high quality advance

directives and further discussion with health professionals. This project aimed to establish a course on empowerment for older people and caregivers in the process of advance care planning (ACP).

**Methods:** A literature search and discussions with experts in palliative care (PC) and intensive medicine (IM) compiled the course concept basis. A focus group and telephone interviews with representatives of the target group were conducted to review the proposed content. Duplication of pre-existing offers was avoided by gathering representatives from organizations who already offer ACP consultations in a second focus group. Two pilot courses containing two lectures and a workshop were conducted at two sites in the canton of Bern (CH).

**Results:** 15 respectively 14 participants took part in the course (mean age 67 resp. 70 years, ranging from 47 to 81 years). Most of them attended as a healthy person with a personal interest, as relative or caregiver and all described their previous expectations as being met. The majority reported to have learnt about the potential benefits of ACP, to feel empowered to discuss their own wishes and to plan for critical situations. Participants especially appreciated in-depth information on ACP, discussion of concrete case studies and the exchange among participants. Challenges were identified regarding care network building at home or defining goals with regard to one's own quality of life.

**Conclusion:** All participants considered a preparatory course with basic information, specific examples and materials concerning future care planning including advance directives as beneficial. The awareness of participants regarding potential benefits but also limitations of anticipatory care planning could be increased.

**Abstract ID: 115**

**Abstract Type: Workshop**

**'It takes a village': Exploring potentials and limitations in applying the death system concept in public health palliative care**

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**Background and Workshop Aim:** Robert Kastenbaum, a U.S.-based psychologist, elucidated the concept of ‘death systems’ in 1977, but it has rarely been utilized in research and practice conducted at the intercept of public health and palliative care (PHPC). In this workshop, we aim to present an overview of the death system concept, and with participants, critically examine its potential utility for researchers and practitioners working in this field. We particularly focus on the death system concept’s potential and limitations in contributing to understanding and evaluating “compassionate communities”.

**The Death System Concept:** Kastenbaum focused on how our encounters with death are systematically related to the societies in which they occur and thus to basic ways of life. He argued that consideration of death systems allows us to be attentive to interconnections and relationships, with respect given to how cultural and societal norms, expectations, traditions, and symbols affect even individual experiences. Kastenbaum’s death system is composed of functions, ordered along a time trajectory from warnings and prediction through social consolidation after death, and each function consists of components of importance, i.e. people, place, time, symbols and objects.

**Workshop Approach:** In this workshop, we provide a short overview of the death system concept as described by Kastenbaum, before briefly exemplifying its’ relationship to empirical work in Australia and in the Swedish DöBra research program. This introduction is intended to stimulate critical exploration with workshop participants about transferability, relevance, and limitations of the death system concept in PHPC initiatives in different settings using varying approaches. Learning objectives of this knowledge exchange include participants’ consideration of the death system concept’s benefits and limitations in: exploring impact of different PHPC initiatives, supporting EoL-related<sup>2</sup> cross-cultural understandings, and helping address levers for cultural and social change.

**Abstract ID: 117**

**Abstract Type: Poster - Community**

### **A workplace compassionate community approach to support bereaved staff in the two national public health organisations in England**

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**Background/aims:** The COVID-19 pandemic has adversely impacted bereavement experience for everyone. Public Health restrictions impacted on visiting the dying, funerals, family support and face to face bereavement services. Staff in Public Health England and the National Test and Trace Service have been working relentlessly on COVID-19 many transferred from other functions and others keeping essential work going. Enforced home working enhanced isolation. COVID-19 pressure plus bereavement was taking its toll on colleagues with little access to support and all faced re-organisation of their employers.

**Methods:** A small group of bereaved staff and others with expertise in bereavement including the National Lead for Palliative and End of Life Care, established Virtual Bereavement Cafés run by staff for staff across the 2 national public health organisations. MS Teams (video teleconferencing, chat, signposting to resources) provided a safe, mutually supportive space for staff to meet virtually. Cafés run fortnightly, 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. Daily Cafés on specific topics were run in Daily Grief Awareness week.

**Results:** Attendance varies 14 to 34 with new staff at each. The level of complicated grief is very high. Topics emerged from shared experiences including: anticipatory, complicated, cumulative, disenfranchised grief and coping with Christmas. Thematic synthesis of discussions and chat identified isolation, distress from limited funeral attendance, presence at death, inability to travel

abroad, work pressure and lack of workplace understanding. Colleagues also wanted tips to support others.

**Conclusions:** Virtual Workplace Bereavement Cafés provide key emotional support during the pandemic. Improvements identified for implementation include: technical enhancements; 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 and respond to feedback.

**Abstract ID: 118**

**Abstract Type: Symposium**

**Navigation interventions to support patients with serious or advanced illness and their family: opportunities and challenges**

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Offering high-quality palliative care to a growing number of people with serious or advanced illness and their family living in the community is a pressing public health concern. These people transition from a serious illness toward end of life. Hence, they often experience a myriad of symptoms and 22 needs encompassing physical, psychosocial and spiritual domains, for which palliative care has been developed. Further, they experience practical challenges in accessing public health and palliative care services, as well as in their daily lives as a consequence of their disease trajectory, such as going to a supermarket or calling for a doctor's appointment. We need a sustainable strategy to meet their growing demand for high-quality health and social care. Navigation interventions using specially-trained lay navigators hold promise to meet this demand.

This symposium brings light to exciting insight on navigation interventions in palliative care and discusses our way forward. Together with experts from Canada, the Netherlands, Belgium and the

United Kingdom, we will present: 1) the implementation and evaluation of an innovative public health palliative care intervention "Nav-CARE", which is a volunteer-led navigation intervention for older people with advanced chronic illness and their family living at home in Canada; 2) the brief history of cancer navigation programs and the need for navigation in supportive, palliative and survivorship care in Europe; 3) the development of a logic model that underpins a navigation intervention for older people with cancer in Europe; and 4) the evaluation of navigation interventions as a supplementary palliative care support service and the need for appropriate outcome measures. Finally, we will discuss opportunities and challenges for implementing navigation interventions in palliative care in different healthcare systems, as well as for evaluating navigation interventions in a palliative care context using different research designs.

**Abstract ID: 119**

**Abstract Type: Poster - COVID**

**Learning lessons from COVID-19 experience for palliative care for people with dementia in England**

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**Background:** The death toll in older adults, especially those who lived in care homes was horrifically high in England during the COVID-19 pandemic in the 1st Wave (W1) - April 2020, with a lower peak in the 2nd Wave (W2) - December 2020/January 2021, before vaccinating as priority the elderly and care homes residents. People with Dementia and Alzheimer's (D&A)) were among the most vulnerable to dying in W1 and W2 - not only from COVID-19.

**Aims:** To analyse mortality in people with (D&A) during the COVID-19 pandemic from COVID-19 and other causes. To identify priorities for Palliative and End of Life Care (P&EOLC) for people with D&A in pandemics.

**Methods:** Mortality data in England for people with D&A as underlying cause (UC) or contributory cause (CC) on death registrations were selected from January 2019 to May 2021. The

UC of death for people with D&A identified as a CC to their death were identified. Deaths (numbers, UC, place of death) were compared between 2019 and 2020 and specifically for these years for the months of W1 and W2.

**Results:** There was a statistically significant 5.3% increase in deaths for people with D&A as UC in 2020 (67,872) compared with 2019 (64,468). However, a more dramatic and significant 69% increase in deaths with D&A as CC in 2020 vs 2019 (44,624 vs. 26,445). The W1 and W2 peaks for D&A deaths were highly significant but different in nature. In W1 (April 2020) the dominance of care homes as a place of death increased to 79% of all deaths in people with D&A UC (8,435) vs. 64% (3,435) April 2019. Also, in W1 there was ~400% increase in D&A CC deaths (10,682 vs. 2,146 April 2019) 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, with increases in Circulatory Disease +44%, Cancer +31%, Parkinson's +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 are extremely vulnerable to risk of death from highly infectious and high fatality respiratory infections especially if living in a care-home. The speed and magnitude of surge in deaths 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 and preparation for all to experience death under strict quarantine rules.

**Abstract ID: 120**

**Abstract Type: Poster – ACP & End of Life communication**

**General practitioners' evaluations of optimal timing to initiate ACP for patients with cancer, organ failure or multimorbidity**

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**Background:** Optimizing the timing to initiate advance care planning (ACP) is difficult, especially for patients with non-malignant disease in community settings. We aim to identify the optimal moment and reasons to initiate ACP in different illness trajectories.

**Design and methods:** In this health records survey study we presented health records to 83 GPs with request to indicate and substantiate what they considered the optimal timing for ACP within two years before death. We performed quantitative and qualitative analyses.

**Setting and patients:** From a regional primary care registration database in the Netherlands, we selected and anonymized 90 health records of patients who died with cancer, organ failure or multimorbidity.

**Results:** According to the GPs, the optimal timing to initiate ACP was 228 days before death (median; interquartile range 392). This moment was closer to death for cancer (87.5 days before death, IQR 302) than for organ failure (266 days before death, IQR 401) and multimorbidity (290 days before death, IQR 389) ( $p < 0.001$ ). The most frequently mentioned reason to initiate ACP for cancer was 'receiving a diagnosis' (21.5%), for organ failure it was 'after a period of illness' (14.7%), and for multimorbidity it was 'age' and 'patients' expressed wishes or reflections' (both 12.0%).

**Conclusion:** The optimal timing for and reasons to initiate ACP differ for patients with cancer and other illnesses, and they also differ between GPs. This suggests that 'the' optimal timing for ACP should be seen as a 'window of opportunity' for the different disease trajectories.

**Abstract ID: 121**

**Abstract Type: Workshop**

**Why is it so hard to become equal partners? Understanding how a Partnership Development framework can shape partnership success**

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**Objectives:** The language of equal partners is fundamental to public health palliative care, yet so many partnerships flounder. In this workshop, two skilled facilitators will introduce participants to understanding the key concepts of partnership, the relevance of partnership principles, the partnership cycle, and the partnership continuum. Participants will apply the Partnership Development framework to their practice of Public Health Palliative Care.

**Interactivity:** This workshop is fully interactive with a maximum of 20 participants, who will work individually, and in small and large groups.

**Learning Outcomes:** Upon completion of the Workshop, participants will have a greater understanding of partnership and how it applies to their current and future collaborations.

**Application to PHPC:** Despite the language of being ‘equal partners’ as a key concept in Public Health Palliative Care, partnership development skills are required to build partnerships that evidence the principles of diversity, equity, openness, mutual benefit and courage. With a sound, evidence-based framework, becoming successful equal partners in Public Health Palliative Care practice is achievable.

**Abstract ID: 124**

**Abstract Type: Workshop**

### Using visual methods in end of life research

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This interactive workshop will explore the role that visual methods can play in end of life research as well as in engaging the public with aspects of death, dying and end of life care. The objective is to expose participants to thought-provoking imagery and to encourage them to consider both the potential as well as the challenges of using/creating visual images in research. The workshop will be grounded in our experiences running a ‘live’ research project – Dying in the Margins – in which we are deploying participatory visual methods with those experiencing poverty and deprivation in Scotland. The workshop will start with a brief examination of some celebrated visual works and

what they reveal about various ‘visual tropes’ as well as noted public responses to them. We will also explore the small body of work that currently exists using visual methods in end of life research. The remainder of the workshop will be spent exploring the potential of these methods, as well as the challenges, both in terms of their practical, technological and ethical usage in the field, and the various sensitivities about how the images are presented to audiences and interpreted by them. We will introduce and debate key themes around representation, evocation and control. Experiences of generating and showing images created specifically by and with participants who are experiencing structural marginalisation will be discussed and key learnings from Dying in the Margins drawn out. Workshop attendees will be put into smaller groups at various points during the workshop and asked to discuss and respond to selected images, as well as to imagine their own (through verbal or written description, sketching, or bringing pictures along with them). Margaret Mitchell, a professional portrait and documentary photographer who is part of the Dying in the Margins research team, will be attending remotely to give her perspective on her aesthetic choices, how she enables participation, the feedback received, and how to deal with the loss of control which comes with showing sensitive images publicly. Finally, space will be given over to a discussion of the power of images to raise public awareness and to agitate for change and for social justice.

**Abstract ID: 125**

**Abstract Type: Free Communication -  
Compassionate cities**

### Ciudades que Cuidan - Cities that Care

*Joan Berenguer<sup>1</sup>, Dolors Rodríguez<sup>1</sup>,  
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The ‘White Paper on Cities that Care’: towards a new paradigm of care

This proposal, prepared by the Mémora Foundation (FM) with the support of the Spanish Federation of Municipalities and Provinces, aims to contribute to the progress towards a caring society that, far from individualism, thinks about collective benefit. Local governments, cities, and municipalities, as agents closest to the citizen, are



the main drivers of care and attention to vulnerable people. To provide them with a roadmap for care, the White Paper on Cities that Care has been presented.

The compendium prepared during the pandemic, between March 2020 and December 2021, collects the reflections of more than 100 experts. These, grouped into 22 specialties, reflected their ideas and experience on care to guide local policies “towards a new paradigm in which care occupies a central place”. As stated in its introduction, the white paper aims to facilitate “a multidisciplinary proposal to move towards a caring society that abandons individualism and thinks about collective benefit”, insisting that all people “at one time or another in our lives, we can be dependent and require care”.

Three phases: reflection, debate and sharing This initiative, which aims to move towards a “new urban model” that addresses the challenges of the future, consisted of three phases.

The first is dedicated to reflection on the main themes that are interrelated with care; from the management of the growing problem of loneliness suffered by many older people, to feminism. But also going through areas such as health, aging or ecology and the environment. “At one point or another in our lives, we may be dependent and require care,” the experts note in this book.

The second phase was a cycle of round table debates, in Webinar format, with the participation of 104 experts and a total registration in the 22 sessions of more than 10,000 citizens, where the fundamental points of the reflections were specified to facilitate their applicability. In this way, they wanted to offer tools so that cities can develop effective ways to implement their local care policies.

The I Conference of Cities that Care was the event that closed the Forum on December 13, 2021. It was attended by people of recognized prestige in the field of care and social care, such as Victoria Camps, philosopher who gave the inaugural conference, and other experts in the fields of aging, health, volunteering, and feminism. In conclusion, the white paper of Cities that Care was presented.

## Abstract ID: 126

### Abstract Type: Poster – Paediatric Palliative Care

#### A 12-month international, observational study of palliative care in childhood cancer patients

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**Background:** It is unclear if the COVID-19 pandemic has increased the proportion of children with cancer progressing to palliative care. In this study, we aimed 1) to establish the proportion of children with cancer started on palliative care, and 2) to determine the factors associated with progressing to palliative care.

**Methods:** Prospective cohort study with data from 109 institutions in 41 countries. Data was collected for all children under the age of 18 years who were newly diagnosed with or undergoing active treatment for acute lymphoblastic leukaemia, Non-Hodgkin lymphoma, Hodgkin lymphoma, retinoblastoma, Wilms tumour, glioma, osteosarcoma, Ewing sarcoma, rhabdomyosarcoma, medulloblastoma and neuroblastoma. Demographics, oncological diagnosis, clinical course, and cancer therapy data were collected. Statistical tests included  $\chi^2$ , and univariate and multivariable logistic regression.

**Results:** 2075 patients were included. 238 patients (11.5%) were started on palliative care. 232 of these patients originally had treatment plans made at the initial multi-disciplinary team (MDT) meeting: 206 (14.6%) of 1413 participants in low-and-middle income countries and 26 (3.9%) of 662 participants in high income countries ( $\chi^2 = 51.502$ ,  $p < 0.001$ ). Multivariable analysis revealed several factors associated with starting palliative care, including low-income (OR 27.13 [95% CI 12.7–58.6];  $p < 0.001$ ), lower-middle income (OR 3.29 [95% CI 2.10–5.17];  $p < 0.001$ ), and upper-middle income (OR 4.82 [95% CI 3.09–7.51];  $p < 0.001$ ) country status, age, male sex, American Society of Anaesthesiologists grade, radiotherapy within 30 days of the MDT, and tumour type.



Other treatment types, changes to treatment due to the COVID-19 pandemic, and SARS-CoV-2 infection status were not associated with starting palliative care.

**Conclusion:** The COVID-19 pandemic has not directly increased the number of children with cancer starting palliative treatment. However, urgent attention needs to be given to the fact that children in lower-income countries are more likely to be started on palliative care.

**Abstract ID: 127**

**Abstract Type: Free Communication - Compassionate communities research**

### **Patient and Public Involvement (PPI) in palliative care research: experiences of the Mesothelioma UK Research Centre**

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**Introduction:** Patient and Public Involvement (PPI) refers to the involvement of patients, public and lay people in the design, conduct and dissemination of research. PPI is a fundamental component of palliative care research internationally but has been reported as complex, difficult and less advanced compared to PPI in other areas of health care research. In 2020 the Mesothelioma UK Research Centre in Sheffield, UK established a PPI panel for mesothelioma, a terminal cancer. The aim of this study was to explore the challenges and successes of PPI in palliative care and mesothelioma.

**Method:** Over a 12 month period data were collected on the number of projects supported by the PPI panel and the different types of support that were provided. Informal feedback from panel members and academics over 12 months was also used to develop a narrative account of key successes and challenges.

**Results:** Over one year the PPI panel contributed to eleven research projects and funding applications. The role of the PPI panel included consultative activities (reviewing funding applications, advising on research questions and methods, advising on dissemination) and collaborative

involvement (membership of steering committees, supporting recruitment, developing recommendations). Collectively the PPI panel have improved connections and partnerships between academics and the public, improved the design and conduct of research in mesothelioma, empowered patients and carers to influence research, and contributed to a culture which supports active patient involvement in research. Challenges have included remote involvement due to COVID-19 and managing discussion around sensitive issues related to palliative care and end of life.

**Conclusion:** PPI contributions to research have expanded over recent years. The experiences of the Mesothelioma UK Research Centre support evidence which suggests that public involvement can make positive contributions to research.

**Abstract ID: 130**

**Abstract Type: Free Communication - COVID-19**

### **The importance of emotional support for relatives before and during the COVID-19 pandemic: a quantitative study among relatives**

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**Background:** Intensive care unit (ICU) admission can have long-term effects on patients and relatives, including anxiety, depression and post-traumatic stress disorder (PTSD). In relatives this is collectively called post intensive care syndrome-family (PICS-F). The uncertainties and visitation restrictions due to the COVID-19 pandemic might have affected PICS-F.

**Aim:** Examine the prevalence of PICS-F symptoms in patients' relatives in six Dutch ICUs, differences before and during the COVID-19 pandemic, and associations with offering emotional support.

**Methods:** A written survey among relatives of ICU patients: 1) with mechanical ventilation pre-COVID-19 (t0: 1-12-2019 – 31-1-2020), 2) with COVID-19 during the first wave and 3) second wave (t1: 15-3-2020 – 15-5-2020 & t2: 1-10-2020 – 31-12-2020), including the Hospital Anxiety and Depression Scale (HADS) and the PTSD Checklist for DSM-5 (PCL-5). Descriptive statistics were used to determine the prevalence of anxiety, depression (HADS subscales  $\geq 8$ ) and PTSD symptoms (PCL-5  $\geq 33$ ) and logistic regression analyses to examine associations of t0, t1 and t2, and offering emotional support with PICS-F symptoms.

**Results:** 328 relatives responded: 95 of t0 (response 62%), 130 of t1 (70%) and 103 of t2 (57%). Of all relatives, 21% experienced anxiety, 19% depression and 9% PTSD symptoms. After adjusting for amongst others the visitation policy, no significant differences were found for PICS-F symptoms between t0, t1 and t2 ( $p > 0.05$ ). Overall the prevalence of PICS-F symptoms was significantly lower in relatives who were offered emotional support compared to those who were not (OR anxiety 0.53; OR depression 0.35; OR PTSD 0.40).

**Conclusion:** During COVID-19 the prevalence of PICS-F symptoms did not change significantly, but offering emotional support was associated with an overall lower prevalence of PICS-F symptoms. This suggests that efforts to provide emotional support for relatives of ICU patients are vital, even outside a pandemic.

**Abstract ID: 132**

**Abstract Type: Poster - Euthanasia & MAiD**

**Untold Stories; Accompanying someone who used medical assistance in dying at the end of life**

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Canada's federal legislation on medical assistance in dying (MAiD) was enacted on June 17, 2016.

To date, little is known about the experiences and beliefs of people who have comprised informal care networks – family and/or friends – who have supported someone throughout the process. The purpose of this research project was to better understand the experiences of family and friends that accompany someone throughout their dying process involving MAiD in the province of Ontario.

This workshop will share findings from 27 interviews that were conducted across Ontario Canada, highlighting the value of participant voices for ongoing healthcare and policy-making practices. The research findings shared will provide insight into the experiences of Ontarians who have accompanied someone who used MAiD at the end of their life. Little attention has been afforded to the social consequences of the aftermath of a medically hastened death experienced by those in the informal support network of the person who has died. Issues relating to access and support will be shared which will encourage participants to reflect on their own role in a compassionate community supporting people after death using MAiD.

The second phase of the study realized eight participants' digital storytelling efforts, curated with members of the research team and developed from the initial interviews. Digital storytelling affords often untold stories the opportunity to be created and disseminated, resulting in transformational experiences for storyteller, viewer and, in this case, research team. During this instructional component of our workshop, both process as well as several products of our study will be explored.

Participants in this interactive workshop will have the opportunity to

- 1) Learn from stories exploring the study participants' experiences of accompanying someone throughout a medically assisted death to appreciate the voices of those directly affected;
- 2) Be introduced/further familiarised with the use of digital storytelling in qualitative healthcare research as it gains momentum as a method/methodology, and
- 3) Bear witness to several digital stories created during this study that highlight patient and circle-of-care focused approaches to end of life.

**Abstract ID: 133**

**Abstract Type: Free Communication - COVID-19**

**Saying goodbye in the age of physical distancing**

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**Background:** The COVID-19 pandemic continues to have a profound impact on people's experience of dying, death, grief and loss. The act of saying goodbye to a person who is dying often begins while a person is dying, before a funeral. COVID-19 has rendered caring, grief and connecting with loved ones at the end of life even more challenging than usual. In these unprecedented and challenging times, it is essential that we learn from our experiences and facilitate creative ways to maintain connections in life and in death. Dedicated COVID-19 research is needed to better understand the physical and emotional toll the virus places on families, carers and patients during this difficult period of restrictions and social distancing.

**Methods:** The purpose of this qualitative research project was to examine the experience of family and informal support networks (friends) who accompanied someone throughout their dying process during the COVID pandemic in in two different geographical regions in the province of Ontario, Canada. Individual semi-structured interviews were conducted with adult family and informal support networks (friends) who experienced the death of someone close to them during the COVID pandemic.

**Results:** This presentation will share findings from interviews which were conducted during the pandemic which will serve to:

1. deepen our understanding of the unique experiences of family members and friends who supported a someone who died during the pandemic
2. increase knowledge about the questions, concerns, and expectations that family and friends have of the healthcare system and social support networks during the pandemic

3. to develop greater insight into the grief rituals, ceremonies and practices people in Northwestern Ontario and the Waterloo region are using during this period of physical distancing

**Conclusion:** In these unprecedented and challenging times, it is essential that we learn from our experiences and facilitate creative ways to maintain connections in life and in death.

**Abstract ID: 134**

**Abstract Type: Free Communication - Various Topics**

**The underused potential of social workers in palliative care in Flanders: A mixed-methods study**

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**Background:** Social workers can have a strong role in professional palliative care, for example, in the detection of social determinants during the end-of-life phase. Furthermore, social workers can be key players in public health palliative care by building bridges between clients, relatives, professionals and the broader community. Nevertheless, social workers are often insufficiently involved in palliative care due to an ambiguous role definition, a lack of specific training and the emphasis on medical aspects.

**Aims:** This study explores the attitudes of social workers in Flanders towards the performance of palliative care tasks as well as the frequency and competency with which they perform these tasks. Furthermore, it examines the extent to which they feel valued by other professionals.

**Methods:** A mixed-methods study was conducted. Social workers from five organisations filled out survey questionnaires: hospitals; nursing homes; neighborhood health clinics; home care, and health insurance services. The results were discussed during focus groups. Quantitative data were analysed by using bivariate analysis and non-parametric significance testing. Qualitative

data were thematically analysed by using the Framework Method.

**Results:** 499 and 24 social workers participated in the survey and focus groups respectively. Respondents have positive attitudes towards palliative care tasks. Yet, for more than 50 % of tasks in the survey, a significant number of social workers indicate a higher score for variables measuring competence in the performance of tasks than variables measuring the frequency with which they perform them. Furthermore, our data shows that respondent social workers do not always feel valued by other professionals.

**Conclusions:** Our study suggests that making better use of existing social work potential as well as clarifying its added value may be a useful strategy for the adequate involvement of social workers in Flemish palliative care.

**Abstract ID: 135**

**Abstract Type: Free Communication - Culture, philosophy and spirituality**

**What does it mean to be 'compassionate'? From the perspectives of a Japanese philosopher**

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**Background:** Translating Allan Kellehear's Compassionate Cities, Public Health and End-of-life Care into Japanese, I have searched for an appropriate Japanese word for 'compassion', that led me to the following questions. What does it mean to be 'compassionate'? What role does 'compassion' play in contemporary society?

**Methods:** I traced some genealogies of the idea 'compassion' in the West and the East, guided by the works of Joseph Campbell, Joan Halifax, Martha Nussbaum, Marcus Borg, and others. I launched into literature research in the fields of mythology, anthropology, religious studies, sociology and philosophy. In parallel, I reflected the dialogical practices of hosting alternative death cafes such as 'cafe mortal' and 'cafe waiting for the wind' in Japan, in pursuit of the interrelation between 'dialogue' and 'compassion'.

**Results:** The word 'compassion' derives from two Latin root words: 'cum' meaning 'together'

and 'patior' meaning 'suffer'. This suggests sharing with another's suffering: to be patient in another's suffering, to bear and support suffering.

As a feeling, compassion is located in a certain part of the body, namely in the loins, both in Judeo Christian and Indian Buddhist traditions. It is the feeling of somebody else in a visceral way, at a level somewhere below the level of the head. In Hebrew context, the word usually translated as 'compassion' is the plural of a noun that in its singular form means 'womb'.

'Compassion' is central to Buddhist teaching. Sanskrit word for it is composed of two words: 'maitrī' meaning 'friendly interest in others' and 'Karuṇā' meaning 'compassion'. The bodhisattva represents the principle of compassion in this tradition.

'Compassion' feels for another, while 'empathy' feels into another. Whereas 'empathy' merges with, includes or identify with another's experiences, 'compassion' is based on the self-awareness of Not-knowing. To understand another, one has to wait in silence, listen and question, 'What do you suffer from?'.

**Conclusion:** Compassionate people turn toward the truth of suffering with the wish to relieve that suffering. As the human response aroused by suffering of others, 'compassion' is essential to a liberal society that Nussbaum aspires to. This is a society of citizens who recognize the needy and vulnerable character of human beings.

**Abstract ID: 136**

**Abstract Type: Poster - COVID**

**Not Just A Visitor; Caregiving experiences in Long Term Care during COVID-19**

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**Background:** At the onset of the pandemic, a friend shared how she was denied access to her mom who was dying in a long-term care (LTC) home. She literally scaled a wall with a ladder that she then climbed to look into her mother's room. This story and the others emerging out of long-term care are heartbreaking. Members of our



community have been denied the opportunity to hold the hands of those they care for as they die, due to pandemic restrictions. Essential caregivers play a critical and irreplaceable role. They are #NotJustAVisitor. The purpose of this research project was to examine the experience of essential caregivers of Ontario residents in LTC during the COVID-19 pandemic. This project captured stories that will provide us with insight about the questions, concerns, and expectations essential caregivers have of LTC and the larger the health system.

**Methods:** Phase one – we conducted an electronic survey completed by family members caring for residents of LTC during the first year of the pandemic.

Phase two: Twenty-five individual semi-structured interviews were conducted from participants who completed the survey in Phase one.

**Findings:** This presentation will share findings from the survey and interviews which were conducted during the pandemic which will serve to illustrate the experiences of family caregivers of Ontario residents in LTC during the COVID-19 pandemic.

**Conclusion:** While health and safety must continue to be paramount as we fight COVID-19, promoting a more compassionate, inclusive visitation protocol that embraces the essential role of family caregivers is imperative. We at a critical turning point where it is essential that we learn lessons that can improve the care, conditions, and outcomes of our most vulnerable Canadians living in LTC. Our research team is working to develop recommendations informed by people who have been impacted by caregiving, isolation, grief and loss during COVID that will directly address identified knowledge, system and policy gaps.

**Abstract ID: 138**

**Abstract Type: Poster - Euthanasia & MAID**

**Information and support regarding euthanasia: a qualitative study on the needs of nursing home residents in the Netherlands**

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**Background:** In the public debate about euthanasia in the Netherlands, the voice of nursing home residents is neither heard nor expressed, so their perspectives and needs are largely unknown.

**Objectives:** We aimed to gain insight in the needs of competent nursing home residents suffering from physical conditions. We investigated the need for information and support concerning euthanasia in the context of end-of-life decision making.

**Methods:** This qualitative study, inspired by the Grounded Theory Approach, is based on in-depth interviews with 15 nursing home residents, who have mentioned euthanasia to their nursing home physician. The participants' age range is between 30 and 90 years. Interviews were conducted from March 2019 until December 2021. Data analysis followed the steps of open and axial coding focusing on the needs of respondents for information and support.

**Results:** Regarding the need for information we found three categories: current knowledge, resources for information, and information concerning the views of the medical practitioner and the institutional policy regarding euthanasia. Regarding the need for support we found four categories: assistance in making a difficult decision, practical support, emotional support, and spiritual support.

**Conclusion:** Respondents for the most part expressed having no present need for information concerning euthanasia in general. Regarding resources for information, most respondents turn for questions first to their medical practitioner. The right to die-society in the Netherlands NVVE is also an important source of information. Respondents did often express a need for information on the views of their physician regarding their willingness to actually perform euthanasia and for the policy of the nursing home. As for the need for support, the study showed that requesting euthanasia in the future is regarded as a difficult decision which will require assistance. Next to practical support, respondents need emotional and spiritual support.



**Abstract ID: 139****Abstract Type: Free Communication - Community engagement and development****Maison Mourance: qualitative study of the vision, organisation and challenges of a community-led end-of-life facility in Brussel***Sabet Van Steenberghe<sup>\*1</sup>, An-Sofie Smetcoren<sup>2</sup>, Kenneth Chambaere<sup>1</sup>*<sup>1</sup>End-of-Life Care Research group, Ghent University & Vrije Universiteit Brussel (VUB), <sup>2</sup>Belgian Ageing Studies, Department of Educational Sciences, Vrije Universiteit Brussel (VUB)<sup>\*</sup>Correspondence should be addressed to: [sabet.vansteenbergen@ugent.be](mailto:sabet.vansteenbergen@ugent.be)

**Background:** ‘Care and living in community’ (CALICO) is an innovative project that aims to develop a new model of community-led care, integrated in a co-housing context in Brussels, Belgium. Within this larger project, Maison Mourance was founded as a community-based initiative for palliative and end-of-life care. It makes a specific connection with birth and mobilizes capacity in the community. This study aims to provide understanding of Maison Mourance in terms of vision at the start of the initiative, organization, roles of various stakeholders and future challenges.

**Methods:** To answer the research objectives a qualitative study was performed consisting of 1 in-depth interview with the project managers of Maison Mourance, 9 in-depth interviews with residents of CALICO and 1 focus group with the steering group of Maison Mourance.

**Results:** Maison Mourance originated from an idea of one founder and culminated into the broader organisation Pass-Ages. Maison Mourance is a nonhierarchical cooperation in which each member is assigned different tasks and roles. It wants to offer a warm and homely environment to people at the end of life and their families. Attention is given to the connection with birth, the central role of the patient and breaking taboos about dying and death. Embedding care in the neighborhood, complementing the existing range of palliative care in the area and creating a network of solidarity were mentioned as added value. Future challenges are financing the project, expanding and keeping the network of volunteers motivated, formulating concrete objectives, designing an evaluation plan and selecting evaluation tools.

**Conclusion:** Maison Mourance is a promising initiative in terms of community-led palliative care. In the creation process of Maison Mourance, several challenges and threats were identified. It will be important to monitor future developments in terms of goal attainment and with an impact on sustainability of the initiative.

**Abstract ID: 140****Abstract Type: Poster – ACP & End of Life communication****Information meetings on end-of-life care organised by GPs and other organisations; do they differ in audience and results?***Annicka van der Plas<sup>\*1</sup>, Roosmarijne Kox<sup>1</sup>, Tessa Bergman<sup>1</sup>, Roeline Pasman<sup>1</sup>, Bregje Onwuteaka-Philipsen<sup>1</sup>*<sup>1</sup>Amsterdam UMC, Amsterdam<sup>\*</sup>Correspondence should be addressed to: [burgeri@amsterdamumc.nl](mailto:burgeri@amsterdamumc.nl)

**Background:** A way to inform older people about end-of-life care, is to organise information meetings by a general practitioner (GP) inviting their own patients, or by another organisation targeting the general population. We looked at differences between attendees of meetings organised by GPs or by another organization in: 1) motivation for attending the meeting; 2) Advance Care Planning (ACP) experience before the meeting; 3) plans to engage in ACP after the meeting; 4) trust in physicians to provide good care at the end of life after the meeting.

**Methods:** A pre-post evaluation study using written questionnaires filled in at the start (T0) and at the end of the meeting (T1). We report on 26 meetings (9 by GP, 17 other) attended by 308 persons.

**Results:** Attendees of GP meetings were older (75 vs 70 years) and had different reasons for attending than attendees of other meetings: more often ‘thinking about the end of life’ (46% vs 33%), and less often other reasons (such as getting information as a carer’ or ‘to prepare myself’) (17% vs 9%). There were no differences between the attendees of the two types of meetings regarding ACP experience beforehand. Attendees of GP meetings more often indicated they intent to discuss their preferences with their GP after the meeting (81% vs 69%), compared to attendees of other meetings. Finally, attendees of GP meetings

more frequently had very much trust in physicians providing good end-of-life care than attendees of other meetings (39% vs 24%). When corrected for age, all these differences disappeared.

**Conclusion:** Meetings organised by other organisations attract a younger crowd. Meetings organised by GPs may result in more ACP behaviour after the meeting because they attract people who are more ‘ready to engage with the GP’, while meetings organised by other organisations may result in earlier awareness and provision of information about end-of-life care.

**Abstract ID: 141**

**Abstract Type: Free Communication - Various Topics**

**From living well with dementia to dying well with dementia: Paradoxes and problems in current approaches to end-of-life care**

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This paper explores current theoretical frameworks that support people, communities and health systems in transitioning from living well, to dying well with dementia. As health and social care services expand to meet growing end-of-life care needs of people with dementia there is a need to think about how the dying process is understood in relation to the life course and how such a framework could work alongside existing approaches to dementia care. The paper argues an approach that embraces the value death holds is vital in shaping a response to care that can meet both the needs and complexity faced by people with dementia. In laying out a complex and often paradoxical terrain, we map Western societies changing approach to death and dying including palliative care and the notion of a good death. By setting out the unique end-of-life challenges faced by people affected by dementia, we discuss the use and relevance of this position as well as the theoretical, ethical and philosophical constructs that have been used to deliver it. We point out that palliative care services are evolving from a service led model to a collective social model where dying is considered a relational and spiritual process

supported by collaborative partnerships. We interrogate such an approach, paying particular attention to the role of social relationships in building a community’s capacity to deliver dementia specific end-of-life care. We conclude by calling for a reimagining of the dying process in dementia as a distinct phase within the lived experience of those with the condition. This requires its own unique theoretical framework supported by an ethic that enables us to see the person dying of dementia as one of intrinsic value.

**Abstract ID: 142**

**Abstract Type: Free Communication - Policy and Vision**

**Processes underpinning care homes’ ability to provide palliative care during COVID-19, and policy recommendations (CovPall\_CH)**

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**Background:** The number of people dying in care homes is projected to increase with population ageing. The COVID-19 pandemic was a stress test for provision of palliative and end-of-life care (PEoLC) in care homes.

**Aims:** To explore barriers and facilitators to providing high quality PEoLC in care homes during COVID-19, and make policy recommendations.

**Methods:** Mixed methods study comprising 1) online survey of UK care home senior staff, identified through care sector networks. The survey was developed from a rapid literature review and included structured and free-text items. 2) Qualitative interviews with individual care home staff, conducted virtually (sampled from the survey). Findings integrated and analysed thematically.

**Results:** 107 survey responses (57 (53%) with onsite nursing care) and 27 qualitative interviews

were included. Three themes were identified. Theme 1: Relational care. COVID-19 disrupted the ability of care home staff to develop and maintain relationships with residents and their families, impairing PEOLC. Theme 2: Pillars of relational care. Essential components required for care homes to maintain relational care during COVID-19 were (i) integration with primary, secondary, community and specialist palliative care services; (ii) digital inclusion; and (iii) workforce support and empowerment. The extent of these components varied across services. Theme 3: (Dis)parity of esteem. The pillars on which relational care is built require strong societal and economic foundations. Care home staff felt their efforts and expertise were often unrecognised and undervalued by the government, media, public, and wider health care system.

**Conclusion:** Recommendations for policy include ensuring emotional and practical support for care home staff, workforce development including education and training, ensuring access to PEOLC advice and support, digital inclusivity, and improved recognition of care home expertise.

**Abstract ID: 143**

**Abstract Type: Poster – Cancer**

### **Patient and Caregiver-reported Acceptability of an “Automatic” Supportive and Palliative Care Referral for Advanced Lung Cancer**

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**Background:** To determine patient-reported acceptability of a phone call from a supportive and palliative care (SPC) nurse offering consultation, automatically after first oncologist appointment for newly diagnosed stage IV non-small cell lung cancer (NSCLC).

**Methods:** This study tested a patient-provider co-designed, automatic referral pathway in a tertiary cancer centre. Two SPC specialist nurses

screened out-patient clinic lists weekly and called all eligible patients offering a home consultation. Eligibility: >18 years, newly diagnosed/suspected Stage IV NSCLC and had first medical/radiation oncologist visit. Patients could have a cancer therapy plan pending, confirmed, or have no further care planned at the cancer centre. Patients/caregivers were surveyed about the acceptability (5-point Likert scale) of consult call, using Sekhon’s Framework of Acceptability domains.

**Results:** In interim analysis, of 63 patients/caregivers contacted and offered SPC consultation, 79% accepted the consult. Of 55 patients/caregivers that agreed to be contacted for the research call: 3 did not recall call, 2 did not consent, 13 were not reached. Of 37 respondents 94.6% rated overall acceptability of the call offering SPC consultation somewhat/completely acceptable. Of 27 patients/caregivers that completed the survey: 30% caregivers, 67% female, 52% ≤65 years, 30% ≤high school education, 58% (n=19) <\$60,000 household income, 85% spoke only English/French, and 74% Caucasian. 93% were comfortable with the call and understood why they received it; 86% thought the call was a valuable; 74% thought the call helped them; 96% thought the call didn’t take much physical/emotional effort; 56% learned about SPC from the call and 100% were not concerned the nurse had access to their contact/health information and were confident in their ability to participate (ask questions/make decisions).

**Conclusions:** Nearly all patients/caregivers found the SPC call offering consultation to be acceptable. Routine calls offering SPC consultation may be an acceptable and timely alternative to awaiting conventional referral by oncologists.”

### *Competing interests*

Dr Sinnarajah reports payments for clinical, leadership and research work from Lakeridge Health, Queen’s University and Alberta Health Services. He also leads or is part of research teams that have received grants from Canadian Institutes of Health Research, Health Canada, Canadian Cancer Society, Canadian Foundation for Healthcare Improvement, Applied Research in Cancer Control, Alberta Innovates Health Solutions, Mach-Gaensslen Foundation, University of Calgary, The College of Family Physicians of Canada, Choosing Wisely Alberta, Alberta Cancer Foundation and Alberta Health Services.

**Abstract ID: 144**

**Abstract Type: Poster - Literacy & Education**

**Development and Testing of the Palliative Care related Knowledge, Attitudes & Confidence in Home Health Care Questionnaires**

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**Background:** Palliative care provides patient- and family-centered care to individuals with serious illness. Home health care (HHC) utilization is increasing in both the U.S. and Europe due to an aging population and patients with multiple chronic conditions, leading to a great need for palliative care in HHC. However, it is unclear if HHC clinicians are prepared to provide such care and how palliative care is perceived by HHC patients and their informal caregivers. Currently, there are no HHC setting-specific survey instruments to measure palliative care-related knowledge, attitudes, and confidence (PC-KAC). This study aimed to develop and test PC-KAC in HHC questionnaires for use with HHC clinicians, patients, and caregivers.

**Methods:** Guided by the 2018 National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP guidelines), we developed two PC-KAC in HHC questionnaires: 1) for clinicians, and 2) for patients/informal caregivers. We conducted a comprehensive literature review, identified existing survey instruments measuring PC-KAC, and adapted scales/questions to the HHC setting. Experts in palliative care and HHC and cognitive interviews with HHC clinicians, patients and informal caregivers helped refine the questionnaires.

**Results:** Our PC-KAC questionnaires are organized by 3 main sections: knowledge, attitudes and confidence; each section contains items relating to the NCP guidelines eight domains of practice. There are core questions, as well as clinician role-specific (for nurses, therapists, social workers) and caregiver-specific items. Questions about demographics, and preferred communication methods, information sources and location of palliative care services are asked at the end. Pilot testing will be conducted with 30 clinicians and 30 patients/

informal caregivers from a large, urban HHC agency to assess validity and reliability.

**Conclusion:** Our PC-KAC in HHC questionnaires are the first HHC setting-specific survey instruments to measure PC-KAC among U.S. HHC clinicians, patients, and informal caregivers. While the questionnaires were developed and tested in the U.S., they can be adapted for different culture and countries. Study results will help inform clinical practice to ensure provision of high-quality palliative care.

**Abstract ID: 146**

**Abstract Type: Free Communication - Compassionate cities**

**Implementing Compassionate Communities Programs to all regions in Thailand: Experience and lesson learn**

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Since 2017, Thai civil society leaders in Promoting Death dying and Palliative Awareness (Peaceful Death group), got to know the Compassionate Cities (CoCi) and Compassionate Communities (CoCo) idea in the APHC2017 conference. CoCo concept had been implemented in Thailand. The process components include 1. Collecting examples about CoCo practices that already exist in Thai society 2. Organizing the CoCo annual academic conference 3. Finding and approaching potential CoCo networks and leaders create CoCo activities in their settings 4. Knowledge managing 5. Training 6. Production of CoCo learning materials. The main sponsor to CoCo programs comes from the Thai Health Promotion Foundation approximately USD 600,000 over the past 4 years.

Till now, more than 20 network partners in all regions in Thailand have participated in the CoCo areas/ issues. More than 300 CoCo Facilitators have participated in the training and continue to expand their knowledge, skills, and attitudes that contribute to healthy living and peaceful dying environment in their communities. Over 10,000 people were benefit from the programs through online and onsite activities. The program also produced more than 5 local research works. At present, the community kindly



expands the work to become a foundation to settle down on ideas.

Important factors in the community work process are various learning tools for discussing death conversations, living will and ACP document writing, mental health support groups to caregivers and healthcare personnel. The CoCo toolkits facilitate CoCo activities by CoCo Facilitators into their community easier. The CoCo core team also tries to offer CoCo models to local community authorities who are interested in caring for the aging society. However, the response from the local and national governments is not much at present.

There are still implementation gaps such as academic production, building collaboration with academic and policy leaders. We believe that the aging society and the need for palliative care situation in Thailand will pressure the public and private sectors looking for expanding CoCo implementation. Until then, CoCo networks would still create working methods and experience prepare collaboration to all partners to build CoCo into all communities in Thailand.

#### **Abstract ID: 147**

#### **Abstract Type: Poster - ACP & End of Life communication**

#### **Talking about death to advanced cancer patients: not if, but how**

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**Purpose:** To determine the knowledge, preferences, and predictors of prognostic information among advanced cancer patients.

**Patients and Methods:** Participants included 195 stage 4 cancer patients in a private tertiary hospital. Patients were informed by their doctor they had advanced cancer less than 6 months to a year of recruitment. Patients completed a validated structured APPROACH questionnaire.

**Results:** Majority (84%) responded that their doctor always explained things in the way they

could understand and always gave them as much information as they wanted about their treatments, including potential benefits and side effects. A good number (69.5%) answered that their doctors always encouraged them to ask all the cancer related questions they had. Most of them (78%) always felt that they were as much involved in decisions about their care as they wanted. Less than half (40.5%) considered themselves very informed regarding how their illness will change over time. Regarding their current treatments, majority (74.5%) think these will help them live longer while most (63%) think these will cure them. Considering their current health condition and treatment plan, almost half (49%) think they are likely to live for more than 10 years. Majority of the participants (67%) did not have anxiety. More participants were suffering from depression, with 34% having borderline abnormal and 26% having higher HADS depression scores. More than half would like to know how long they are likely to live under various treatment options, with 32.5% preferring to know in general terms and 24% wanting to know in specific terms. Patients with higher HADS depression scores were almost three times (95% C.I. 1.05-7.04) more likely to want to know how long they are likely to live under various treatment options ( $P = .039$ ). More than half (61.5%) would you like to be at home during the last days of their life.

**Conclusion:** Almost half of the advanced cancer patients have misperceptions about prognosis. Since these patients, especially those with depression, would like to know how long they are likely to live under various treatment options, doctors should not hesitate to talk about death so they can actively participate in decision-making and express their preferences about end of life care.

#### **Abstract ID: 148**

#### **Abstract Type: Free Communication - Culture, philosophy and spirituality**

#### **"Bayanihan:" The cultural practice that turns health care workers & ordinary Filipinos into heroes during the pandemic**

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In the Philippines, the “Bayanihan” spirit is one of communal unity and cooperation to help fellow countrymen in times of need. Bayanihan is a Filipino word derived from “bayan” meaning community or nation. Bayanihan is also derived from “bayani,” meaning a hero, and bayanihan literally means “being heroes” to the community. Among the first casualties of COVID-19 were a number of doctors who heroically risked their lives for their patients.

Inspired by the Bayanihan spirit, hospitals, private sector, and government units rose to the challenge of the pandemic. The Medical City hospital came up with: a two-in-one hospital system to make it a safe place for all, comfort-focused care pathway for COVID patients, COVID home care program, and teleconsultation services. During the lockdown, doctors and nurses were provided free transportation services, food, and PPEs by generous donors. Private schools allowed their premises to be used as quarantine facilities. The Bayanihan spirit was also in the ordinary Filipinos whose children made thank you cards for healthcare workers to lift their spirits and in those who started community pantries and food distribution for the poor.

While many critically-ill COVID patients succumbed to the disease, they received the best care possible, pain was controlled with palliative care, and someone was with them when they died. While graveside services were limited to 5 to 10 people, online Novenas to pray for the souls of the dead became common practice among families and friends. For COVID patients who recovered, their discharge was accompanied with claps and balloons from doctors and nurses who share their joy at their new lease on life. For non-COVID patients, they felt safe enough, due to the two-in-one hospital system of The Medical City, to continue their treatment.

Bayanihan inspires Filipinos. We believe that together we can survive and thrive. We always bounced back from the heaviest typhoons, floods, volcanic eruptions, and earthquakes. We keep our smiles. That’s because we know that when we need help, our fellow Filipinos will unite to help us. Indeed, while the COVID pandemic continues its devastating effects, it has made heroes of health care workers and ordinary Filipinos.

**Abstract ID: 150**

**Abstract Type: Free communication - Arts and end of life**

## **No Barriers Here – A Creative Approach to Advance Care Planning Conversations with Communities often underserved in Healthcare**

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**Background:** No Barriers Here was co-produced with a group of adults with learning disabilities, an Art Psychotherapist and a hospice in 2020 during the first wave of the covid-19 pandemic. It uses arts-based approaches to explore and enhance advance care planning conversations with people and communities who experience systematic differences and inequalities accessing healthcare services, particularly in palliative and end of life care.

This award-winning approach has since been developed further and used with communities who may be excluded by identity, culture, ethnicity or race.

**Methods:** A co-production group was established with members of Black, Asian and minority ethnic communities, hospice staff (Palliative Care Inclusion and Community Partnerships Lead, clinical and community engagement staff) and an Art Psychotherapist. The co-production group worked together to further develop the original No Barriers Here methods to explore if the model could be successfully used with other groups often underserved by healthcare services. Three rounds of workshops were held in community settings, using arts-based approaches. A thematic analysis of the artefacts and objects created was undertaken, and interviews were held with participants.

**Results:** The emerging results and early findings will be presented for the first time at PHPCI 2022. Emerging themes include:

- The importance of building trust and community engagement

- The impact of co-production on engagement
- The need for a flexible approach and importance of listening
- The role of less verbal approaches and a focus on relationships

**Conclusion:** This project seeks to improve engagement with people and communities who are often marginalised and underserved in palliative and end of life care, and across health care more widely. It adopts the principles of public health palliative care and community engagement. Co-production methods and principles were adopted throughout.

No Barriers Here shapes rich and valuable dialogue within communities and is an effective tool in engaging in early conversations at a community level.

**Abstract ID: 151**

**Abstract Type: Free Communication - Compassionate cities**

### **Differences in urban and rural approach to build Compassionate Cities: Swiss examples**

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**Background:** Most people in Switzerland would like to spend the end of their lives at home, but this is only possible for a few of them. Compassionate Cities as understood by Public Health Palliative Care International, advocate for a new culture in which dying, death and grieving are not located in specialised institutions, but remain a part of public life. These cities are crucial allies for democratising Palliative Care.

**Methods:** The city of Bern and a regional association of rural communities in the Swiss mountain region decided to participate in a project on Compassionate Cities in 2020. Approaches differed: while a network of preexisting organisations and institutions (ranging from city office for elderly affairs to palliative care services) was quickly formed in the city, most of these organisations were missing in the rural community. There,

first steps were undertaken by an organisation for the elderly and the municipal administration.

**Results:** The city network directly began implementing the Compassionate City by organising public events, developing and publishing a charter, and creating volunteer groups. Meanwhile, the rural network first had to familiarise itself with the topics of end of life and palliative care. These had to be integrated into the local policy on ageing to guide the development of a Compassionate City.

**Conclusions:** In both urban and rural areas, Compassionate Cities need to be fully embedded in partnerships between health facilities and local social care and community structures. In rural areas, the degree of organisation of palliative care is often lower than in urban areas. However, this is not necessarily a disadvantage for the rural periphery. The actors delivering services for the elderly population can be central partners for Compassionate Cities in rural, as well as in urban areas. However, the prerequisite is that ageing policy takes on an integrating function, and is not limited to infrastructure planning.

**Abstract ID: 152**

**Abstract Type: Poster - Community**

### **Supporting compassionate communities in dying, death & bereavement by providing space for orgs to gather, discuss & learn**

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**Background:** Check-in and Chat sessions were created in response to a post lock-down, online survey (Nov 2020) sent to community organisations across two Scottish localities. The Marie Curie survey received 74 responses and evidenced a request to create a regular, local session offering support, signposting, information and resources relating to end of life care and planning as well as more information on end of life services available locally.

**Purpose:** To equip staff, volunteers and service users of local community organisations with tools, knowledge and connections to help build compassionate communities at a grassroots level.

**Methods:** Using local experts and Marie Curie's Community Engagement Officers a calendar of online sessions has been brought to the

communities covering subjects such as ‘Grief in the Workplace’, ‘What to Say?’, ‘Caring for the Carers’, ‘Finances and Support for Carers’.

Sessions offer a relaxed, safe space to build local relationships, find out about services and learn skills, all helping improve conversations around dying, death and bereavement.

**Results:** In 2021 nine online sessions were facilitated. An average of 15 people registered, 10 attended, and 157 expressed an interest, demonstrating a need for learning opportunities around dying, death and bereavement locally with organisations whose main purpose is not palliative and end of life care.

**Conclusion:** Breaking down barriers to conversations about dying, death and bereavement can happen everywhere. The Check-in and Chat sessions are helping to equip a wide range of professionals from many backgrounds to have more confidence in thinking / talking /planning / connecting/ taking action in relation to these subjects, reducing any discomfort. Sessions are to continue in 2022, aiming to support at least a further 40 people in the year ahead.

**Abstract ID: 153**

**Abstract Type: Free Communication - Various Topics**

**Live well, die well (iLIVE): Cohort and interview study protocol of an international research programme**

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**Background:** Patients with serious illness may face a number of physical and psychosocial challenges in their last months of life. As part of this process, patients may need to constantly manage expectations, concerns and preferences regarding complex decision-making processes in end-of-life-care. Changes resulting from a deterioration in health status can also lead to shifting expectations, concerns and preferences as well as different cultural contexts may result in different expectations, concerns and preferences regarding end-of-life topics. The view on health, life, and death as such is a matter that is highly dependent on the patient's culture and is of utmost importance for those providing end-of-life-care. The international EU funded iLIVE project is aiming at providing better understanding of current experiences of dying.

**Methods:** In an international ongoing cohort study, patient recruitment is being conducted in Argentina, Germany, Iceland, New Zealand, Netherlands, Norway, Slovenia, Spain, Sweden, Switzerland and United Kingdom. Participants (those identified with an ‘estimated’ prognosis of < 6 months) are surveyed with validated tools assessing domains of quality of life and resource use, symptom burden, well-being and concerns. Data is being collected upon patients' inclusion, one month after inclusion, and, if applicable, in the last days of life and 90 days post-bereavement with an identified key-relative. Qualitative interviews with five patients/family members/ health care professionals in 10 countries will provide an in-depth understanding of experiences, expectations and preferences.



**Results:** We expect to provide insight into similarities and differences in patient's and relatives' expectations, concerns and preferences regarding the last months of life as well as healthcare worker's experiences with care for dying patients.

**Conclusion:** Data and analysis from the iLIVE project will contribute to the improvement of care for the dying and enable normalizing death and dying, whilst also giving evidence on how well relatives felt supported at the end of the patient's lives. Data will also be used to begin the development of cultural frameworks that may serve to optimize patient care in the last months of life.

**Abstract ID: 154**

**Abstract Type: Workshop**

### **A design approach to transdisciplinary end-of-life care challenges**

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#Max Kleijberg and Marieke Sonneveld will both facilitate the workshop.

**Background and objective:** Dying, death, loss, and care are experiences that are profoundly impactful and transcend disciplinary boundaries. The field of health promoting palliative care aims to improve end-of-life (EoL) related experiences by connecting formal and informal EoL-care, striving towards health equity at the EoL for marginalized groups, and increasing death literacy among the general population. To this end, various disciplines need to integrate in collaborative development processes, which requires transdisciplinary creativity. Design addresses complex issues through creative transdisciplinary collaboration, developing products and services, improving experiences, and changing perspectives. Designers have developed tools and processes to facilitate transdisciplinarity in various contexts and have begun to apply these to address EoL-issues. The objective of this workshop is to explore the potential of a design approach to transdisciplinary collaboration in the context of health promoting palliative care.

**Workshop content and learning outcomes:** Based on our own experiences as designers and researchers working with health promotion and palliative care, we will discuss some of the

possibilities and challenges of working “designerly” in this field. In smaller groups, we will then apply design tools and processes to explore creative ways of addressing complex EoL-related issues. These design processes and tools include e.g., design thinking, co-creation, user journeys, and rapid prototyping to create design interventions. Participants will have a hands-on introduction to the “language” of design and gain experience in re-framing the transdisciplinary challenges they may encounter in their own practice and research. Learning outcomes for workshop participants include an increased understanding of the potential of design and working designerly in the field of health promoting palliative care.

**Abstract ID: 155**

**Abstract Type: Poster - Education**

### **Knowing, being proficient, and being in palliative care starts in education, but does it?**

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**Background:** The Palliative Debate revealed that the Flemish society demands appropriate and timely palliative care (PC). One of the resulting ambitions is the improvement of training in PC for healthcare providers. The goal of the project EduPal Vlaanderen is to map the presence of PC themes and the acquisition of PC competencies in Flemish nursing programmes from the perspective of the teachers, students and the work field. The results should lead to an action plan to accomplish change and improvement and to give PC a full place alongside other care topics in the Flemish nursing curricula.

**Methods:** To determine the extent to which basic competencies in PC are embedded in the programmes, a curriculum analysis was carried out in 10 of the 11 Flemish university colleges. With online surveys, the last year students as well as the professional field were asked how they experienced the PC education and competencies.

**Results:** The curriculum analysis revealed a number of remarkable facts. With the exception of ‘general medicine and medical specialisms’, PC is hardly dealt with in the six other European

health care domains and usually PC is discussed as a separate topic rather than an integrated part of a broader care subject. It is also striking that the time spent on PC topics during the 4-year nursing programmes varies greatly: from 2h to 31h for the compulsory courses. Moreover, PC is provided mostly in a fragmentary way and in none of the analysed programmes, PC is dealt with during all of the 8 semesters. Another point of attention is that in most programmes, PC is represented by a single lecturer and other lecturers seem to be hesitant and difficult to convince to address the topic in their classes.

**Conclusion:** With the student and working field surveys still being processed, this project is in full development. From the curriculum analysis, it appears that there is room for optimization of the education in PC: the current approach is not sustainable and impeding the development of a PC attitude required in each care setting. In the presentation, an integrated view of the 3 perspectives will be presented and working points will be specified for nursing programmes to improve the knowledge, skills and attitudes of graduating nurses to provide quality basic PC.

**Abstract ID: 156**

**Abstract Type: Poster – Euthanasia & MAID**

**Relatives of cancer patients' experiences regarding the interaction with healthcare providers during a euthanasia process**

*Charlotte Boven<sup>\*1</sup>, Let Dillen<sup>2</sup>, Lieve Van den Block<sup>3,4</sup>, Ruth Piers<sup>1</sup>, Nele Van Den Noortgate<sup>1</sup>, Liesbeth Van Humbeeck<sup>1</sup>*

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**Background:** Recent studies underscore the importance of a patient/healthcare provider/family triad in euthanasia care. As such, our aim was to explore how family experiences the interaction with healthcare providers (HCPs) during a euthanasia trajectory.

**Methods:** 22 semi-structured interviews with family members of cancer patients. Transcripts were analyzed using the Constructivist Grounded Theory approach.

**Results:** The moment participants are informed about the euthanasia request of their loved one, they become part of the journey towards the euthanasia execution. During this period participants place their loved one's needs central, while their own needs are put aside. At first, most relatives are not immediately on board with the request and try to find peace with it whether or not with the help of HCPs. During this process they can move from understanding why the patient requests euthanasia to comprehending the request, so they can give him/her permission to let go. Being part of this process is described as a 'rollercoaster of emotions', where the mixed feeling of relief and sadness is commonly experienced.

**Conclusion:** Participants find it important to be involved in the euthanasia process as early as possible. However, they describe this as an intense and uncertain period. They appreciate being guided through this process with the help of HCPs before the loss but most of them have little or no expectations regarding follow-up contact. These insights emphasize the importance of family-centered care in the context of euthanasia and can substantiate existing clinical guidelines.

**Abstract ID: 157**

**Abstract Type: Poster - Euthanasia & MAID**

**Healthcare providers' experiences regarding the interaction with family during a euthanasia process: A qualitative study**

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**Background:** In 2019 a total of 2655 people died in Belgium due to euthanasia, of which 62.5% had cancer. Recent studies underscore the importance of a patient/healthcare provider/family triad in euthanasia care. As such, our aim was to explore how healthcare providers (HCPs) experience the interaction with family of cancer patients in euthanasia care.

**Methods:** 45 semi-structured interviews with Flemish HCPs (15 physicians, 17 nurses and 13 psychologists), working in hospitals and/or home-care. Transcripts were analyzed using the Constructivist Grounded Theory approach.

**Results:** Participants had diverse experiences regarding the interaction with family, which can be visualized as a continuum ranging from negative to positive. The achieved degree of serenity is the main contributor in determining their position on the aforementioned continuum. To create this serene atmosphere, HCPs take actions underpinned by two attitudes (wariness and meticulousness), which are guided by different considerations. These considerations are subjected to a learning process (of trial-and-error) and can be categorized into three groups: 1) ideas about a good death and its perceived importance, 2) having the situation well under control and 3) self-reassurance.

**Conclusion:** In Belgium, relatives do not have a legal mandate in the decision-making process of euthanasia. Nonetheless, the interviews and previous literature show that HCPs acknowledge relatives as important actors within euthanasia care as they want to ensure that family can cope with the loss. These insights may shape family-centered care in the context of euthanasia and can substantiate existing clinical guidelines for HCPs.

**Abstract ID: 158**

**Abstract Type: Free Communication - COVID-19**

### **Massive shift in proportion of cancer patients dying at home instead of hospital in England during COVID-19 Pandemic**

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**Background:** Enabling patient choice in place of death has been a key element in Cancer and Palliative Care Policy in England since 2008. Most patients would choose home. In 8 years (2011-19) the increase in proportion of cancer patients dying at home was small (28.9 to 31.1%)

and hospital remained the most common place of death. In 2020, despite ~ 100,000 extra deaths from COVID-19, the number who died from cancer was almost unchanged (138,026, 2020 vs. 137,851, 2019). In 2020, the number and proportion of deaths at home from all causes increased 155,815 (27.4%) from 120,467 deaths (24.3%) in 2019.

**Aims:** To investigate the impact of the first year of COVID-19 on place of death for cancer patients in England.

**Methods:** National Mortality data used to identify cancer deaths (underlying cause) and place of death in England in 2019 (baseline) and 2020 (first year of COVID-19). Comparisons were made by: 20 top cancer types, age group and Local Health Administration (LHA).

**Results:** Of all deaths at home, the proportion from cancer increased 36.5% (2020) vs. 35.5% (2019). A significantly greater number (14,112) and % of people died from cancer at home 41% (2020) vs. 31% (2019) e.g. Lung cancer +2,554. In contrast hospital deaths from cancer reduced 35% (2019) to 29% (2020), Care Homes 15% to 13%, Hospice 15% to 8%. Death at home increased for all 20 cancer types (12/20 by >10%) range 5.8% to 12.9%. For all cancers except haematological (3/20), deaths at home exceeded deaths in hospital and for 11/17 types for the first time ever. % people dying at home increased for all ages by ~10% to: <75 years (42%), 75-84 (43%), >85 to (37.2%). Home deaths from cancer increased in all 106 LHAs in England: inter-quartile ranges 28.8-34.1% (2019) to 38.7-44.2% (max 51.8%) (2020).

**Conclusions:** In England, the COVID-19 pandemic caused a massive increase in the proportion of cancer patients (+10%) dying in their own homes – more than 8 years of strategy had achieved (+2.2%). 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 institutions. The quality of care provided is not known. If choice played a significant role, and the current increase is sustained, community palliative care resource must be increased to support more cancer patients to die at home.

**Abstract ID: 159**

**Abstract Type: Poster - Loss & grief**

**Walking the walk in connection: Experiences of healthcare providers with bereavement care in oncology**

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**Background:** In 2020 cancer remained the leading cause of death worldwide, accounting for almost 10 million losses. Hence, healthcare providers (HCP) are often confronted with the care for bereaved relatives. Knowledge about bereavement care offered to relatives of oncology patients is however scarce. This study aimed to explore how HCP working in hospitals or palliative home care services experience the provision of bereavement care.

**Methods:** Seven online focus groups with in total 32 Flemish HCP who are working in palliative home care services or a hospitals. The transcripts were analyzed using thematic analysis.

**Results:** Bereavement care is considered as walking the walk with patients and relatives. Ideally this starts at diagnosis of a life limiting disease, as this enables HCP to build relationships and to be there at everyone's time and space. Bereavement care is a delicate balancing between connecting as a person and supporting as a skilled HCP. Conditions that would help HCPs with this balancing act are education, intervision, organisational mandate, shared vision, teamwork, and trustworthy referral addresses: conditions that are not always met.

**Conclusion:** HCP experience bereavement care as a meaningful but complex act of care in a context of uncertainty. HCP would benefit from having clear and realistic clinical and organisational guidelines, which can support their role and responsibility regarding offering these services. In addition, future research should explore relatives' expectations regarding bereavement care, as this would aid HCP to tailor their support.

**Abstract ID: 160**

**Abstract Type: Poster - Equity and Access**

**Improving equity of palliative care provision within advanced heart failure via a realist synthesis: PalliatHeartSynthesis**

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**Background:** Heart failure (HF) is a major public health issue, affecting over 26 million people globally and expected to increase significantly with ageing populations. There is substantial evidence on the benefits of integrating palliative care (PC) in HF management for improving patient and carers health and wellbeing, and cost savings for healthcare systems. However, inequity of PC provision for HF patients is an ongoing problem with poor implementation globally. The aim of this study is to identify what works, for whom and in what circumstances when integrating PC and HF in order to improve equity of palliative care provision for patients with HF.

**Method:** This project used realist synthesis methodology, as this is the best approach to synthesise the evidence for complex health care interventions depending on context and people involved. We used Pawson's five iterative steps for realist synthesis. We have recruited an international stakeholder group comprised of content experts, healthcare professionals in HF and PC delivery, and patients with HF who have advised throughout the study on what works, for whom, in what contexts to inform recommendations for integrated PC and HF services.

**Results:** 1768 texts have been identified through literature searching with 1088 articles included for full-text screening. We will report on why inequity in implementing PC into HF management exists and what we can do about it. At the time of presentation results will be completed and we will present our findings.



**Conclusions:** The evidence for integration of PC into management of patients with HF can no longer be ignored in a civilized society, where we are measured by how we treat the most vulnerable, and have a civic duty to provide the most up to date healthcare from cradle to grave. This research uses innovative methods to provide practical recommendations for policy and practice to improve provision of PC for diverse and historically excluded populations such as patients with HF.

**Abstract ID: 161**

**Abstract Type: Free Communication - COVID-19**

**Palliative care should be part of a public health pandemic response – insights from transferring the National End of Life Care I**

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**Background:** Palliative and End of Life Care (P&EOLC) services normally have a relatively fast turnover of patients, however, the monthly/yearly numbers in any setting/geography is relatively predictable. The National End of Life Care Intelligence Network (NEoLCIN) in England evaluates and explores many aspect of Palliative Care need, provision and equity issues and trends (over years). In the COVID-19 pandemic, the NEoLCIN transferred to work on real time surveillance of COVID-19 as the only team with expertise in the social care sector in Public Health England.

**Aims:** To describe the temporal and geographical variation changes in need for P&EOLC services during the COVID-19 pandemic in impact on need 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 Local Health Administrations (LHAs). 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 LHAs were described using interquartile range (IQR).

**Results:** In 2020 deaths increased by 15% (73,459) vs. 2019 and 10% (29,652) more in 2021 (January to July) vs. 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 LHAs in 2020 the IQR variation in increase in deaths was: care home (14% - 29%), home (23% - 34%), hospital (2% - 13%), hospice (-23% to -4%). In April 2020 across 106 CCGs the IQR variation in increase in deaths was: care home (137% - 275%), home (58% - 105%), hospital (46% to 96%), hospice (-27% to +17%).

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

**Abstract ID: 171**

**Abstract Type: Poster - ACP & End of Life communication**

**Developing an advance care planning website for dementia: Integrating a user-centred approach and patient and public involvement**

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**Background:** Alzheimer Europe and other organisations advocate for the involvement of people with dementia and their families in health-related research to ensure the relevance of findings for them. Patient and public involvement (PPI) can achieve this. We describe how we used PPI in combination with a user-centred approach, which focuses on end-users' needs, to develop an advance care planning (ACP) website designed

for and with people with dementia and their family carers.

**Methods:** We formed a PPI group composed of people with dementia ( $n = 2$ ), family carers ( $n = 2$ ), and other stakeholders working on dementia or palliative care ( $n = 4$ ). After a meeting to discuss the website's concept, its content was developed iteratively, and 4 prototypes were presented to the PPI group, each continually adjusted according to the feedback received. In parallel, we conducted user-testing with 9 people with dementia and 17 family carers using the think-aloud method and a usability survey for each prototype.

**Results:** Outcomes of user-testing and PPI contributed substantially to the design of the ACP website, including an interactive tool and videos. Feedback on the prototypes identified content that was either missing or too difficult and technological issues, thereby ensuring the website's user-friendliness and relevance. Due to limited access to our target population, recruitment was challenging. Despite additional strategies, only 9 people with dementia participated in user-testing out of the 18 targeted.

**Conclusion:** Working with people with dementia and family carers through user-testing and PPI produced an ACP website that is seen as user-friendly and relevant by end-users, and that can be further evaluated for feasibility. PPI input alongside user-centred research enabled us to obtain relevant, insightful, and valuable feedback that informed the ACP website development. Our experience also revealed potential recruitment difficulties which should be considered in future studies.

**Abstract ID: 173**

**Abstract Type: Poster - ACP & End of Life communication**

**Mirror methodology: using marketing codes for better talking about end-of-life**

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A mirror methodology is a group made up of a representative panel of people to deepen the understanding of field perceptions and to test hypothetical solutions, reinforce them, adjust them before finalizing them. Mirror methodology

has shown its effectiveness in industry. The French National Center for Palliative and End-of-Life Care (Centre national des soins palliatifs et de la fin de vie, France - CNSPFV) stepped out of its comfort zone by borrowing this working method from the field of marketing. It therefore created a mirror group of users of the health system in order to establish a link between the French experts who work within structures related to the end of life and the entire French population. This abstract describes the methodology and the first experiences of it.

The mirror methodology is not a working group but a meeting and exchange space for the whole community (local and national administrations, hospitals, private structures, experts, citizens, etc.). Thus, its purpose is not to produce documents but to test and make known those that exist, in particular those produced by the CNSPFV and which relate know-how, experiences or interesting innovation. They can also point out to the bodies concerned, if necessary, gaps in doctrine that should be filled. Experience shows that the presence of a mirror group provides a relevant and substantiated analysis of the language elements of communication. It also allows either to reinforce working hypotheses, or to develop approaches in order to better get French citizens to adhere to what is put in place to ensure them a quality end of life.

**Abstract ID: 174**

**Abstract Type: Poster – Organisation of PC**

**How is end-of-life care organised around the world?**

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**Context:** International studies have highlighted a very heterogeneous level of development of palliative care (PC) between countries around the world. This unique panorama deepens this question from an essentially qualitative angle to understand how end-of-life care and the palliative approach are organized around the globe, particularly in countries characterized by middle or low income and a level of weak development.

**Method:** A literature synthesis has been carried out with data collected in April 2021 from the MEDLINE/PubMed, and Palli@Doc databases

and with institutional information and reports. Data have been used to identify major operating models of PC shared by certain regions of the world. Where appropriate, innovative, or specific initiatives, which deviate from Western habits, have been more precisely detailed.

**Results:** Three major groups of countries have been identified, within which the palliative approach adopted seems relatively homogeneous. In the “charitable” model, predominant in South Asia and Africa, PC is practiced within and by the community and mainly financed by donations. In the hospital-centred model, observed in East Asia and in several Latin American countries, PC is specialized and practiced mainly in the hospital settings. In the mixed home-hospital model, identified in certain Central and South American countries, care is initiated in the primary sector and the objective is to ensure a continuum between the different levels of care. The development of PC is also influenced locally by plural and intertwined factors such as history, culture, religion, demographic characteristics, or epidemiological changes in each country.

**Conclusion:** This international panorama presents the main currents of palliative practice existing in the world. It analyzes how countries, despite the difficulties, work to develop a PC services adapted to the needs of their population, to sociocultural requirements and to the challenges of tomorrow.

**Abstract ID: 175**

**Abstract Type: Workshop**

### **Leading cultural change in health care: practice-based evidence**

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**Background:** Management literature provides bookshelves full of theory on how to lead change projects. Leading and facilitating change projects however in such complex systems as those we encounter when implementing compassionate cities, ask for more than just a theory. In the cities of Bruges and Herzele, we try to capture the elements that make the difference in achieving cultural change around caring, dying and grieving. As for the stakeholders, we consider the perspectives of the community as well as service

providers, since we observe differences in and even conflicts between perspectives.

**Objective:** The workshop aims to present and discuss a hands-on model from a practice based evidence point of view. We present frameworks, values and beliefs the facilitator/project teams used to start the Compassionate Cities project in Belgium. We share observations of where these frameworks stay upright or seem to fail. We discuss the why's we observed as well as alternative strategies we developed to cope with obstacles. We present a first model in which we try to capture the key elements of leading change in complex systems, levers on handling interdependence between those elements. We invite participants to check their experience against ours and each other's, using a world café format based. By thoroughly debating experiences, will evaluate to which extent our model is coherent and applicable in other Compassionate Cities. We conclude with a plenary exchange and wrap-up on the objectives of the workshop.

**Learning outcome:** At the end of the workshop, participants will have obtained increased awareness of looking at Compassionate Cities from a complexity point of view; increased awareness of the underlying processes of cultural change; increased awareness of the key elements a leader/facilitator can steer upon to create the best possible context in which cultural change can take place; new inspiration through input of fellow participants on how to further implement the change process they themselves are in.

### **Application to public health palliative care:**

The workshop is aimed at sharing and providing guidance for those who want to introduce cultural change in public (palliative) health care as a policy maker, leader or facilitator.

**Abstract ID: 176**

**Abstract Type: Workshop**

### **“Let's Talk About It” Compassionate Ottawa (CO) presents three resources for community engagement and empowerment in compassionate community work**

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Compassionate Ottawa is a community organization that aims to change the way we think about dying, death, loss and grief and to build the capacity of the people of Ottawa to care for one another during times of crisis and stress. Strategies include community empowerment, community-engaged education and participatory action research.

**The objective** of this workshop is to introduce and demonstrate use of three innovative resources created to stimulate compassionate community development.

**The resources** include:

- 1) An 8-minute video (English /closed captions in French) on the development of Compassionate Ottawa, created to be used as a catalyst for community leaders to develop their own compassionate community initiatives. The video is accompanied by a Discussion Guide and detailed Handbook of Compassionate Ottawa's development, along with lessons learned.
- 2) Seven digital stories made by volunteers with personal experience, on the theme of giving and getting help in later life. Digital storytelling is a creative process where individuals design 3 to 5-minute videos that pair audio recordings of personal narratives with visuals and music. Stories in both English and French are accompanied by a Discussion Guide. Stories are viewed and discussed in small groups to stimulate conversation and personal reflection.
- 3) A book chat Discussion Guide and Facilitator Guide for the book "Talking About Death Won't Kill You" by Dr. Kathy Kortess-Miller. Book chats involve individuals who independently read a book and then meet as a group to discuss the major themes and personal impact.

**Learning Outcomes:**

- Participants will learn how the resources were developed and used in online sessions during the pandemic.
- Participants will experience how the collaborative and collective discussion within the group fosters critical, reflective inquiry and creates change in participants' knowledge, attitudes and behaviour.

- Evaluation data from pilot tests will be presented to demonstrate their impact on viewers.

**Application to PHPC:**

- Participants will discuss how the resources can be used to support compassionate community development.

**Abstract ID: 177**

**Abstract Type: Free Communication - Equity and Access**

**Access to palliative care in the UK for people experiencing homelessness due to immigration issues**

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**Background:** In the UK, there are a growing number of non-UK nationals with immigration issues (failed asylum seekers, undocumented migrants, visa overstayers, some EU nationals). They are often not entitled to benefits including subsistence or housing support. Some are also not entitled to free secondary healthcare. This can result in destitution and homelessness, particularly if people become ill and unable to work. This research explores access to palliative care for people experiencing homelessness (PEH) who are destitute as a result of these issues

**Methods:** This project has 3 parts 1) hospice staff survey, 2) focus groups with inclusion health staff and other experts 3) interviews with PEH with unsettled immigration status and poor health. This presentation will focus on parts 2 & 3. Qualitative data were analysed using thematic analysis.

**Results:** The complexities of entitlement to NHS care and to accommodation and subsistence from local authorities were explored. Hospital clinicians were not always clear about their role in decision making around the right to receive NHS treatment when people were unable to pay. This knowledge is vital for effective patient advocacy.



This advocacy could be difficult, time consuming and emotionally draining. These challenges were compounded by understaffed, overstretched teams that did not always have the necessary specialist knowledge. For people with unsettled immigration status who were sick, fear played a role in late presentations and the use of false identities.

**Conclusions:** well resourced, specialist teams, working in collaboration with a range of different professionals are key to effective support and advocacy for PEH with poor health and unsettled immigration status. Greater awareness of people's rights and better access to legal advice is needed in health and social care services, as well as recognition of the emotional toll on staff while trying to provide support for this group towards the end of their lives.

**Abstract ID: 178**

**Abstract Type: Poster – Community**

### Exploring the support needs of the British Muslim Community with palliative care needs – a collaborative qualitative project

Briony Hudson<sup>\*1,2</sup>, Gemma Clarke<sup>1,3</sup>,  
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**Background:** The COVID-19 pandemic revealed and exacerbated many long-standing inequalities. The highest age-standardised mortality rates of COVID-19 deaths were within ethnic groups that make up the largest proportions of the British Muslim community. Little research exists exploring the particular experiences of British Muslims with palliative care needs, and their caregivers during the COVID-19 pandemic.

**Methods:** This work a collaboration between Marie Curie and the Muslim Council of Britain (MCB). Together we developed a topic guide to explore experiences during the pandemic. Peer researchers (members of the British Muslim community) were recruited by the MCB and trained by Marie Curie on research and qualitative interviewing. The peer researchers then conducted telephone interviews with British Muslims with palliative care needs, and their informal caregivers. Participants were recruited through MCB,

and snowball sampling. Thematic coding of the transcripts was undertaken by members of the Marie Curie research team. Themes were discussed and developed into recommendations in collaboration with the MCB.

**Results:** Peer researchers conducted 11 interviews, 10 in English and one in Urdu. Interviews included four participants with palliative care needs and seven informal caregivers (age range 35–80). Diagnoses included heart failure, dementia, frailty and multiple sclerosis. Themes related to physical and mental impacts of the pandemic, access to healthcare and the pivotal role families played in supporting people. The role of technology and faith groups were also explored.

**Conclusions:** Structural recommendations, as well as recommendations for organisations, communities and individuals were co-produced. The recommendations centre on providing culturally aware and appropriate support in a variety of formats and champion the inclusion of the voices from a diverse range of backgrounds in the development of government and organisational policies and practices.

**Abstract ID: 180**

**Abstract Type: Free Communication - Loss and grief**

### Formalising peer mentoring relationships between bereaved parents in the hospital and hospice sector

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**Background:** Contemporary approaches to care of the bereaved encourage a compassionate approach within the community. Such an approach, that sources strength from community networks, also seeks to normalise the experience of suffering, death and dying. Often the most solace can take place in relationship with a bereaved peer. In the words of Joanne Cacciatore 'when we look into the eyes of another, someone who has known suffering, without a word we know that they know, and there is something painfully restorative in that mutual recognition'. This presentation shares development and activation of

two peer mentor programs for bereaved parents based in Queensland, Australia; one based within the state's tertiary children's hospital, the other in Queensland's only children's hospice.

**Methods:** Co-design methodology, a partnership between bereaved parents and program leads, informed creation of the CHQ Bereavement Service Peer Mentor Program (PMP) and Hummingbird House Companion Program. Each service sort to activate connections between bereaved peers throughout Queensland, with the program hub based in the state's capital, Brisbane. Training of Peer Mentors sort to build knowledge and confidence to enable support of bereaved parents in their early grief experience.

**Results:** The CHQ Bereavement Service Pilot PMP has trained 15 Peer Mentors with 13 newly bereaved parents now accessing peer support. Evaluation will be complete by May 2022. The Hummingbird House Pilot Companion Program launches in February 2022 with six bereaved parents participating in training. Evaluation will take place in August 2022.

**Conclusion:** Bereaved parents often describe immense loneliness and isolation following the death of their child. Peer mentoring relationships create a space for shared understanding, normalising of grief and 'mutual recognition' beyond what can be gained from non-bereaved friends or professional relationships. Such an approach also encourages a sustainable approach to service delivery.

**Abstract ID: 181**

**Abstract Type: Free Communication - Compassionate cities**

### **Building Compassionate Communities: An Integrated Approach to Raising Awareness of Palliative Care and Advance Care Planning**

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**Background:** Compassionate communities represents an innovative public health. Since the World Health Organization's Ottawa Charter in 1986 and Allan Kellehear's seminal publication in 2005, this initiative has been widely implemented

around the globe. Emerging reviews reflect diverse strategies and a lack of consensus on best practices regarding development and evaluation. This project outlines an integrated strategy across a regional (province or state) reflecting a broad range of stakeholder organizations.

**Method:** A three phase stakeholder strategy has been used to identify, understand and engage individuals and organizations with an interest in palliative care and advance care planning. A systematic review and environmental scan of educational tools was conducted. A representative public panel will support five working groups. Robust communications and marketing plans will inform the development of creative content to promote the uptake of these tools. Overlapping networks of government partners, hospice and palliative care societies, libraries and professional organizations are attending an action planning workshop to coordinate activities.

**Results:** To date we approached 9 government ministries and 800 community organizations. A nominal group technique was applied to 42 government initiatives and has resulted in the development of three projects representing the first three of eight responding Ministries: Seniors and Housing, Municipal Affairs and the Public Service. A total of 52 individuals and organizations participated in a targeted e-blast media campaign and in-depth survey. Palliative and Hospice Societies, libraries and legal associations represent the early adopters of this integrated and comprehensive approach.

**Conclusions:** An integrated and comprehensive approach to implementation of Compassionate Communities on a province-wide scale provides insight into early successes and encouragement for further development.

**Abstract ID: 182**

**Abstract Type: Free Communication - Culture, philosophy and spirituality**

### **What do research studies identify as spiritual and religious interventions at the end-of-life? Findings from a Cochrane review**

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**Background:** Studies show that addressing the spiritual and/or religious needs of people approaching the end-of-life may benefit both their spiritual wellbeing, and also their wider wellbeing. A 2012 Cochrane review of randomised controlled trials (RCTs) of spiritual and religious interventions for adults with terminal illness identified 3868 citations, but just five RCTs, all in the USA and of varied quality. We updated this for 2011-21.

**Methods:** We systematically searched six databases for RCTs of spiritual or religious interventions with adults with terminal illness between Nov 2011 and Dec 2021. We included interventions conducted as a sole study focus or as elements of wider studies. Our 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 texts for retrieval, assessed these for inclusion, discussed differences, and agreed a final set. Data extraction is currently underway, and a detailed evaluation of study findings will follow.

**Results:** We identified 2551 potentially relevant citations, retrieved 94 texts, and included 38, a far larger number and proportion than the first review (38/2551 vs 5/3868).

Included studies were internationally diverse, from Europe, the Americas, Africa, and the East, and varied widely in definition and design. Some were components of a general palliative care intervention, others explored dignity therapy, group or individual psychotherapy, or other therapies. Nurses, physicians, psychologists or chaplains delivered the interventions, as individual professionals or collectively. Our review will be complete in spring 2022, with full details of all studies.

**Conclusion:** More RCTs are being conducted in this area, with a wide diversity and little consistency in definitions of spiritual and religious interventions. Greater similarity of approach and

design would enable better comparisons between studies.

**Abstract ID: 186**

**Abstract Type: Symposium**

### **Community development around serious illness, dying and loss: Stories and perspectives from three countries**

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**Objective:** Compassionate communities aim to increase people's capacity in serious illness, death and loss, and are often based on an asset-based community development approach involving various stakeholders, such as civic society. In this symposium we offer three different perspectives from three countries on the process of compassionate community development.

- From a micro-level, Louise D'Eer provides insight in developing a neighbourhood civic engagement initiative around serious illness, dying and loss in Sint-Kruis (BE). Important elements include: the motivation of the people participating, and the contextual and structural facilitators and barriers in the development process.
- From a meso-level, Libby Sallnow presents the Social Capital Model, based on researching the Compassionate Neighbours initiative in London (UK). This model illustrates the reciprocal nature of partnerships in community development, resulting in social capital for all involved parties.
- From a macro-level, Mary Lou Kelley shares the 'Developing a Compassionate Community Model', which is based on Canadian research (CA) and observing compassionate community initiatives around the world. It is a conceptual model that provides guidance in community development, and explains the change process that communities go through to increase whole community capacity around serious illness, dying and loss.

The three presenters will end the symposium with a shared summary of critical success factors in

compassionate community development. They will also discuss the applicability and transferability of these success factors to other communities, inviting perspectives and experiences from the audience.

**Abstract ID: 188**

**Abstract Type: Free Communication - Community ACP**

### Stakeholder Perspectives for Improving Palliative Care and Advance Care Planning in the Community

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**Background:** Stakeholder engagement is imperative in developing Compassionate Communities initiatives. By adapting a state-of-science stakeholder analysis framework, we developed a comprehensive strategy to identify, understand, and engage stakeholders. This analysis was conducted on the premise that the community organizations operate as intermediaries for sharing knowledge more broadly and promoting better access to palliative care and advance care planning (ACP).

**Methods:** Structured searches of public databases, nonprofit inventories and supplementary online sources were used to identify stakeholders in Alberta, who were invited to participate in an online survey. Literature review resulted in eight domains being included in the survey: knowledge, interest, position, leadership, resources, power, alliances, and social innovation. Likert scales were used to measure respondents' overall perceptions of the nine domains and open-ended questions were examined using content analysis.

**Results:** Fifty-two participants responded to the survey (response rate 50.5%). 34 respondents represented their organizations while 18 as individuals. At organizational level, stakeholders' knowledge about compassionate communities scored lower than that of palliative care and ACP. Likert scale ratings showed that participants were interested in leading initiatives, sharing resources, joining others, enhancing inclusion, and changing existing perception. In contrast, organizations' self-perceived influence in raising public awareness of palliative care and ACP within their own communities received one of the lowest ratings.

When asked to list ideas that would help establish a compassionate community, four themes emerged: awareness, education, resources and networks.

**Conclusion:** Stakeholders across societal sectors genuinely had an interest in informing public initiatives. Recommendations derived from the survey will inform the development of effective engagement strategies for Albertans.

*Funding*

Government of Alberta, Canada

**Abstract ID: 189**

**Abstract Type: Free Communication - Community ACP**

### Utilizing a life journey and multi-sectoral approach to promote advance care planning

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**Background:** While advance care planning (ACP) policy implementation in the healthcare sector has had a moderate impact, we postulate greater uptake if a life journey and multi-sectoral approach is taken to embed ACP into the social fabric. Within an individual's life journey there exists milestone events and routine touchpoints (e.g., driver's license, first home, retirement) that serve as opportunities for advance care planning messaging. To build capacity for ACP in the life journey for a diverse public, a multi-sectoral approach is taken to engage and educate institutes and organizations in a community.

**Methods:** We have engaged the provincial government, legal, financial, libraries, and cultural and faith organizations through information sessions and surveys to gauge interest and capacity to champion ACP within their respective sectors. A public forum will be held in March 2022 to coordinate collaboration and provide an opportunity for community stakeholders and organizations to co-create an action plan to promote and educate ACP for the public.

**Results:** There is a need for ACP education, navigation and resource support within



the community. We are building a toolkit for stakeholders and organizations which will include comprehensive knowledge about ACP, region specific resources and navigation, and creative content for implementation. Working groups will be convened to inform community-based strategies and methods to disseminate ACP to the greater public. An emphasis is placed on reaching groups that have been historically neglected from public health initiatives such as homeless populations and cultural and faith groups so that all members of a community are equipped to complete ACP.

**Conclusion:** Utilizing a life journey and multi-sectoral approach provides the framework for an action plan to promote, disseminate resources, and provide early navigation on ACP to a diverse public beyond the healthcare system.

#### *Funding*

Government of Alberta, Canada

**Abstract ID: 191**

**Abstract Type: Free communication - Arts and end of life**

#### **The Amfora conversation: providing language near the end of life**

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An innovative best practice empowering patients.

A jug with two ears – an amphora – is a storage place for precious things: oil, grain or wine. The amphora is also the symbol of the purpose of the Amfora conversation: capturing someone's precious story, store it carefully and pass it on to the loved ones as a tangible memory.

People approaching the end of their life often feel the need to express their feelings and thoughts. While much attention goes to conversations about care (advance care planning) and about the course of someone's life (life stories), far fewer initiatives exist that focus on the essential question: what does it do to you to be incurably ill?

The Amfora concept is innovative because it is based on the journalistic interview method. The interviewer (a caregiver, volunteer, . . .) asks

specific questions about the person's fears, regrets, faith and hopes with respect to their illness, their lived life and the approaching end. This method implies there is no patient-caregiver relationship and there is no dialogue. The interviewer listens and captures the essence of the person beyond the chronic condition, in his fragility and strength. For most people the Amfora conversation has a deep liberating effect.

The Amfora practice contributes to wellbeing and quality of life on three levels: the ill person is being and feeling heard during the conversation; the conversation opens doors to other meaningful conversations with loved ones and also caregivers, thereby increasing job satisfaction; and the conversation supports the grieving process of relatives since it results in an artistically crafted booklet, a forever memory.

The underlying aim of the Amfora concept is to help creating connection near the threshold between life and death, and beyond. It can be considered as an example of how to implement the fourth pillar of palliative care, empowering patients to have their spiritual/existential needs fulfilled. The practice has proven to be of great significance to all those involved.

In order to disseminate the practice, Dutch speaking professionals and volunteers from hospitals, palliative care networks, facilities for people with disabilities and elderly care can participate in a four-day training on how to conduct an end-of-life interview and translate it into a written story. This is how Amfora expertise in the workplace becomes anchored in (Belgian) healthcare.

**Abstract ID: 192**

**Abstract Type: Poster - Cancer**

#### **A Controlled Clinical Trial of the effects of Meditation on patient's Perceptions of their Quality of Life in an Acute Hospital**

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**Introduction:** Meditation has not been widely studied in the acute hospital setting. The overall purpose of meditation is to improve the quality of the patient's experience of living with advanced

incurable disease, recognizing that this may also be a unique way of offering both spiritual and psychological support.

Several studies have highlighted the beneficial impact that meditation can have on the lives of those living with cancer diagnoses. A study conducted by Zhang MF et al showed that mindfulness-based interventions such as art therapy, effectively helped to alleviate anxiety & depression among patients with malignancy.

A meta-analysis & systematic review by Xunlin NG et al which examined 29 studies exploring the topic of the effectiveness of mindfulness-based interventions among cancer patients and survivors, showed that patients receiving mindfulness-based interventions reported significantly lower anxiety, depressive symptoms, fatigue, & stress, along with greater quality of life (QOL), than patients in the control group.

A study performed in Harold's Cross Hospice in Dublin on 'The evaluation of the effects of touch therapies on patients' perceptions of their quality of life in palliative care settings' is a major source of inspiration for this clinical study, & the methodology is very closely aligned too. Our proposed study is essentially a replica of the Touch Therapies Controlled Clinical Trial done in Our Lady's Hospice two decades ago. In this study, the intervention group had a significant reduction in anxiety levels & significant improvement in overall 'Hospital Anxiety & Depression scores'. There was a greater shift in cue nomination by the post intervention group in SEIQoL-DW which may indicate that patients receiving 'touch therapy' adapt faster than those who are not receiving it. While all patients found the experience 'relaxing' on 'critical incidence' analysis, how this was interpreted by different patients was very individual to them, i.e. for one person 'touch therapy' was 'revitalizing' and for another it was 'sleep inducing'. One patient identified that it may have 'triggered the calm' and for another it was a 'safe' and 'caring' experience. These comments support the other findings in the study in relation to reduced anxiety levels & positively affecting patient's perceptions of their QoL.

**Aims:** The aim of this study was to evaluate the effects of meditation on patient's perceptions of their Quality of Life (QoL) in an acute hospital setting. The assumption is that patients receiving

'meditation' will have a higher perceived QoL and a greater degree of adaptation in their 'living with' and 'dying from' their disease, than patients who do not receive 'meditation'. In short, the fundamental aims of our study are hence as follows:

1. To assess change in QoL in patients receiving mindfulness and compare with a group of patients not receiving mindfulness.
2. To assess the dynamism of QoL in both groups and analyse differences between groups.
3. To assess the level of anxiety and mood in both groups, analyse change over time and compare differences.
4. To help establish mindfulness as an integral part of a palliative care service.

**Methodology:** A controlled clinical trial methodology is proposed. 60 consecutive patients admitted to the oncology ward in GUH will be randomly allocated to either a control or treatment group. Control group being those receiving normal specialist and active group will also receive a twice weekly session of meditation. Schedule for the Evaluation of Quality of Life-Direct Weighting (SEIQoL-DW), Symptom Bother (SB), Symptom Bother interference with QoL (SBIQoL), Hospital Anxiety Depression (HADS), and in the 'active' group 'Critical Incident technique' information will be gathered from the patients, their words, to describe the effects of the 'meditation'. SEIQoL-DW, SB, SBIQoL, elicits; cues/areas that matter to the patient's QoL; level of functioning for each cue; the relative importance of each cue; symptoms nominated or the severity, interference, frequency, 'bother' of symptoms. Response Shift of SEIQoL-DW and HADS will also be assessed, i.e. how patient's 'memory' affects outcome measures.

**Findings & Results:** Clinical trial application has been submitted to Ethics Committee for review.

Results of the study to date: the learning and development of skills surrounding how to compose a patient information leaflet and patient consent form, as well as how to perform risk assessment for clinical research trials.

**Conclusion:** This study hopes to demonstrate that the intervention of meditation, has positive benefits for the person with advanced disease and

positively affects QoL versus patients who have standard acute hospital care.

**Abstract ID: 193**

**Abstract Type: Poster - Euthanasia & MAiD**

### **The Canadian Medical Assistance in Dying (MAiD) Curriculum Development Project**

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Medical Assistance in Dying (MAiD) was legalized in Canada in 2016, ensuring the right of every adult Canadian with incurable disease to access a medically assisted death if specific criteria are met. Since then, over 20,000 Canadians have used MAiD to end their suffering, the overwhelming majority by intravenous medications administered by a clinician.

Reflecting democratization of health care, MAiD came into practice after a change in federal legislation derived from case law rather than through changes in health care. As a result, clinicians who initially came forward to support patients requesting MAiD did so without the benefit of MAiD-related education and training. Clinicians adopted a 'see one - do one - teach one' approach; local and regional 'best practices' evolved at different rates. The Canadian Association of MAiD Assessors and Providers (CAMAP) was created to help support clinicians providing MAiD-related care. A national standardized approach to training on best practices to ensure MAiD is provided appropriately is lacking.

In 2021, CAMAP was approached by Canadian parliamentarians to create a national educational MAiD curriculum. The Canadian MAiD Curriculum Development Project (CMCDP) is CAMAP's response to this request. Federal funding was received from Health Canada.

The CMCDP is overseen by a Core Committee comprised of MAiD content experts from across Canada. This Committee reports to CAMAP and to a National Steering Committee comprised of stakeholders to ensure equity and diversity in the curriculum content. Each Core member chairs a

diverse Working Group tasked with developing an educational module for one of eight topics: Foundations, Initial Clinical Conversations, Assessments, Provisions, Capacity and Vulnerability, Complex Scenarios, Mental Health, and Clinician Resilience.

The curriculum will be developed with synchronous and asynchronous on-line learning formats, available in French and English, and can be delivered through in-person workshops. A rigorous implementation and research-focused evaluation process involving a variety of end-user groups from across Canada is planned. The final curriculum will be approved by our national medical and nursing colleges and will be promoted and sustained by CAMAP with ongoing support from our National Steering Committee.

**Abstract ID: 194**

**Abstract Type: Poster - Cancer**

### **Cultural and religious beliefs and traditions affecting attending the clinic for cancer and palliative care in Uganda. Findings**

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**Aim:** To examine cultural beliefs and traditions affecting access for cancer care and palliative care in Uganda.

**Methods:** This was a cross-sectional mixed-methods pilot survey (n=30) conducted between September and November 2020 in three regions i.e. central, western, and southwestern Uganda. Purposive sampling was used. 10 participants comprised of five cancer patients and five key informants (KIs) i.e. spiritual and traditional leaders were recruited from each region. Structured face-to-face interviews were used.

**Results:** Quantitative findings found participants attributed the cause of cancer to; infection and catching from others (66.7%), witchcraft (46.7%), Heredity/genetics (30.0%), and offending/punishment from God (23.3%). Commonly used forms of medical advice and treatment for cancer were; spiritual (80%), traditional herbal (76.7%), modern (76.7%), and traditional (23.3%). Barriers to cancer care access were; cost and advice from others (family, friends, health

workers etc.) each at 93.3% and distant health-care services (53.3%).

Findings from qualitative interviews yielded two broad themes; (1) socioeconomic constraints and (2) cultural barriers

**Discussion:** Beliefs and traditions as a subset of culture are very varied and complex in nature. They vary from person, place and time. They directly impact and people's values, norms, cultural practices, religiosity and spirituality. Hence, they greatly influence their healthcare seeking behaviors and choices for cancer and palliative care. Poor knowledge about cancer, poverty, accessibility challenges and strong cultural beliefs are commonest barriers to cancer care access.

**Conclusion:** Findings underline the significant existing knowledge gap about cancer and its treatment. There is need for; (1) Multi-stakeholder approaches to address this gap i.e. reduce barriers to care access, (2) Education to demystify myths and false beliefs, (3) Adoption of culturally appropriate and affordable care

**Abstract ID: 195**

**Abstract Type: Poster - ACP & End of Life communication**

**To make and execute decisions throughout life - a model to facilitate self-determination in residential care**

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**Background:** To make and execute one's own decisions is self-evident to most adults but for older persons in residential care self-determination can be limited by dependency and routine based care. This abstract presents the fourth study in a project that aimed to develop a model to facilitate self-determination for persons in palliative phase in residential care.

**Methods:** The findings from the three previous studies together with strategies found in a literature search, and a theoretical framework of person-centered care and relational autonomy constituted the foundation for the model developed in the present

study. A participatory research design using appreciative inquiry in focus group discussions with staff, residents, and care managers was used to develop the model. The research process and the model were audited by two expert groups: a scientific reference group and a dementia-specialist reference group. The model was thus developed by combining practical and theoretical knowledge in cooperation between end users, experts, and researchers.

**Results:** The result is the model 'To make and execute decisions throughout life' that speaks with the older persons voice addressing the staff of the residential care facility. The model has a core message: 'In my way, at my pace, with the help of you' which is reinforced by the seven categories 'See me as a competent person', 'Show me professional consideration', 'Meet me in a trustful relationship', 'Give me opportunity to a meaningful and safe day', 'Support me in being independent', 'Let me have power over my own life', and 'Help me to plan my end-of-life care'.

**Conclusion:** The core message 'In my way, at my pace, with the help of you' is a clear reflection of the theoretical framework of person-centered care and relational autonomy as it renders the importance of acknowledging both the abilities and the uniqueness of the person, as well as the need for professional assistance. The model can inspire staff to see their own contribution to the residents' self-determination and help them to find ways to facilitate it despite obstacles such as cognitive and physical impairment and staff shortage. The model is currently being tested in a residential care facility in Sweden.

**Abstract ID: 196**

**Abstract Type: Poster - Cancer**

**Lived experiences of health professional cancer patients and survivors. A phenomenological evidence**

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**Objective:** The study sought to; (1) examine healthcare professionals' (HCPs) lived experiences of cancer and (2) generate evidence to inform policy and clinical practice for cancer care



**Methods:** This was a qualitative phenomenological study conducted on HCPs who are ill with, and or survived cancer in Uganda. The study was approved by Hospice Africa Uganda Research Ethical Committee (HAUREC) protocol number HAUREC-079-20. Purposive sampling was used to recruit eligible participants. A demographic form and an open-ended topic guide were used to collect. Face-to-face and telephone interviews were conducted in English, audio-recorded and data saturation was reached. Colaizzi's framework of thematic analysis was used.

**Findings:** Eight HCPs cancer patients from medical, allied health, and nursing backgrounds participated in the study. Their mean age was 56 years with age range of 29-85 years. Five were female and three were male. Four broad themes emerged from the interviews; (1) pre-diagnosis and receiving bad news experience, (2) impact of cancer on the HCPs, (3) healthcare system and treatment experiences, and (4) the gaps and what needs to be done.

**Conclusions:** Many HCPs are increasingly receiving a diagnosis of cancer. Becoming ill with cancer is a challenging experience for the professional. It is associated with remarkable disruptions and suffering in nearly all domains of their quality of life i.e. their professional identity and work, social, emotional, physical and economic. Like lay cancer patients, HCPs cancer patients as well experience practical challenges in accessing cancer care. The study showed that health workers are not well prepared to handle their colleagues (HCPs) who become cancer patients. Policy makers and other stakeholders need to work towards improving cancer care services for both the HCPs who are patients of cancer, and also the general cancer patients.

**Abstract ID: 201**

**Abstract Type: Free Communication - Equity and Access**

**Equity-oriented care and Structural Vulnerability- the ABCs of its application to our work in Public Health Palliative Care**

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Many people and communities face significant, enduring structural and systemic barriers that severely affect access to health and social care, create health disparities and impinge on people's quality of life. Framing hospice, palliative care and EOL care around equity and social justice issues are absolutely fundamental to the PHPC approach, yet many of us have only partial familiarity with current terminology and concepts. In this highly interactive workshop we first help participants gauge their own familiarity with contemporary concepts related to equity, diversity, and inclusivity and then help them situate these within palliative/EOL care and PHPC. We provide 3 examples from the Canadian experience of communities of people who benefit greatly when key dimensions of equity-oriented approaches to care are considered and use these examples to facilitate awareness and learning for participants. We conclude with a group discussion that consolidates overarching themes to provide direction for broad, enduring and global application. The overall objective of the workshop is to prepare participants to readily mobilize on Equity Diversity and Inclusion issues in their own Public Health Palliative Care work.

**Abstract ID: 202**

**Abstract Type: Poster – Family caregivers**

**Cultural adaptation and validation of Sinhala version of Modified Caregiver Strain Index**

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**Background:** Caring for a family member in need of palliative care casts a huge impact on caregivers. The assessment of caregiver burden is an integral component of long-term care planning of older adults with chronic diseases and malignancies. Studies regarding the prevalence and patterns of caregiver burden in Sri Lanka is lacking. This study presents the results of validation of the Sinhala version of the Modified Caregiver Strain Index (S-MCSI).

**Methods:** The MCSI was translated from English to Sinhala by two translators, blinded to each other. The two translations were combined and translated back to the original language by two separate translators. After verifying the content validity, unambiguity and clarity of items in a focussed group discussion, the pre-final version was tested among 192 volunteers selected from National Cancer Institute, Colombo South Teaching Hospital, and Teaching Hospital Ratnapura. Data were analysed for internal consistency and item-total correlations. Factor analysis was done using Varimax rotation with Kaiser normalization. A Scree plot was also made to determine the number of factors.

**Results:** The mean (SD) age of subjects was 61.4 years (12.6). The total S-MCSI score ranged from 0 (3 subjects) to 26 (2 subjects). The overall Cronbach's alpha was 0.80 while item-total correlations varied from 0.34 to 0.62 (except the item 12 'caregiving is a financial strain', which had 0.11 correlation) indicating high measurement reliability and internal consistency. Factor analysis showed three-factor structure explaining 57% of variation. Factor 1 included items 1, 2, 3, 8, 9 and 10 while Factor 2 consisted items 4,5,6 and 7. Factor 3 included items 12 and 13.

**Conclusions:** The S-MCSI is a reliable and a valid tool to be used in assessing caregiver strain. The poor performance of item 12 can be attributed to the cultural sensitivity in Sri Lanka where the financial strain imparted by caregiving is not considered to be a socially acceptable norm.

**Abstract ID: 203**

**Abstract Type: Free Communication - Equity and Access**

### Improving Equity of Access to End of Life Care - An Appreciative Enquiry Study

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**Introduction:** Socioeconomic status, ethnic origin, diagnostic group, age, and geographic location among a multitude of sociodemographic factors can affect an individual's access to End-of-life care. Actively identifying successful initiatives to reduce health inequalities in end-of-life

care facilitates knowledge-sharing and scaling of interventions across regions.

**Methods:** An appreciative inquiry approach was used to solicit, via NHS England communication channels, case studies of interventions to improve access to end-of-life care in under-served groups. Factors contributing to each initiative's success and aspects of each initiative's design that could be applied to different contexts, were identified through qualitative framework analysis.

**Results:** 14 case studies were shared from across England. These described interventions such as 24/7 telemedicine services; community link nurses; specialist end-of-life social prescribing; and community engagement events. Initiatives were aimed at increasing access in a range of under-represented groups depending on local priorities. Joint working, between levels of care and across private, public, and civil society organisations was identified as a key marker of success.

**Recommendations:** Providers of end-of-life care should maintain equitable access as a core principle when planning new initiatives or evaluating existing services. Collecting and sharing data on existing interventions and their outcomes can help scale and spread initiatives to improve access. Agreement on a core set of data for this purpose would enable more effective research, evaluation, and transferability of good practice.

**Abstract ID: 204**

**Abstract Type: Free Communication - Family caregiving**

### Easy Language Empowers all Carers to Engage in Decision-Making

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**Background:** Worldwide up to 20% of the population has reading difficulties. Easy language is a further development of plain language texts. It enhances text accessibility and readability for people with and without reading problems than plain and standard language. Recently, there were developments in the field and increasing usages of plain and easy language in self-management

leaflets. The linguistic accessibility of patient assessment instruments, however, is mostly lacking. Despite the increasing clinical and research need for patient- and proxy reported outcomes.

To empower as many nursing home frontline staff and family members as possible with our program, we provide an accessible clinical instrument. Our presentation illustrates easy language use with the Swiss Integrated Palliative Outcome Scale for People with Dementia (IPOS-Dem).

**Method:** We adhered to a six-step process to adapt IPOS-Dem for the Swiss context. Easy language for German-language regions has standardized guidance. Our team, therefore, reworked the scale to adhere to word difficulty, word selection and sentence length guidance. Easy language specialists supported this forward translation step.

**Results:** Text can be presented on a spectrum of comprehensibility levels: Easy language is most accessible to an elaborate level with languages for special purposes. However, there are drawbacks to delivering (or asking) information like this. The distinctive reductionist presentation of easy language texts may have a repulsive effect on people without reading difficulties, shifting the issue from accessibility to acceptability. However, cognitive interviews and our clinical partners in the IPOS-Dem project confirmed the relevance and importance of accessible, easy-to-use instruments for clinical practice.

**Discussion:** The Instrument was adapted beyond plain language to allow proxy assessment for people with advanced dementia. A particular highlight is the downstream empowerment of family members to participate in decision making. However, further psychometric testing of the adapted IPOS-Dem is indicated and underway.

**Abstract ID: 205**

**Abstract Type: Poster - Health Promotion**

**Loneliness at end of life: A public health approach to promoting the health and wellbeing of terminally ill patients and their carers**

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**Background:** Loneliness is a public health issue impacting on a person's health and wellbeing which can lead to increased reliance on health and social care services. Evidence suggests feelings of loneliness are heightened for people impacted by terminal illness. This study aimed to identify solutions to loneliness among terminally ill patients and their carers.

**Methods:** An explanatory multi-method study comprising of an online survey (n = 68, response rate 30%) and three online focus groups (n = 15) with palliative and end of life care health and social care practitioners. Data were analysed using descriptive statistics and thematic analysis.

**Results:** Findings will be discussed under one of the project's key themes: (1) The loneliness antidote: Befriending and companionship services. Social and emotional connectedness was highlighted as key to alleviating experiences of loneliness for people with a terminal illness and their carers. Peer-support groups and services such as rehabilitation programs and complementary therapies were highlighted as necessary for providing respite and psychosocial support for people with a terminal illness and their carers. Key aspects of these services included meeting others experiencing similar situations and providing companionship for those lacking social networks during the end of life period.

**Conclusion:** There is a need for policy drivers for commissioning and promotion of befriending, peer support and companionship services across communities. These services need to be co-produced with people impacted by terminal illness to ensure they meet the needs of those experiencing loneliness within this population.

**Abstract ID: 206**

**Abstract Type: Workshop**

**Using a health promotion approach in palliative care research**

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**Background:** Growing evidence shows that using a health promotion approach in palliative

care can also have a positive impact on health outcomes in patients, their families and communities. A health promotion approach focuses on factors such as empowerment, attitude and self-efficacy that stimulate health and wellbeing and on enabling individuals to have control of these factors and to make healthy choices even when confronted with life-threatening illness.

**Objectives:** To improve knowledge and skills to use a health promotion approach in palliative care research by 1) sharing experiences (challenges; facilitators, barriers) with the use of a health promotion approach in palliative care research and providing inspiring practices and 2) discussing the (potential) impact for people confronted with serious illness, communities, health care services and policy. This workshop will also schedule time for any questions or other ideas related to using a health promotion approach in palliative care research.

**Workshop format:** The speakers will shortly (10') and interactively present their work and experience with using a health promotion approach in palliative care research. Following these presentations, ideas for using a health promotion approach in future palliative care research will be discussed. For example: how to apply principles and practices of health promotion; how to co-create and design studies with the target group and other potential end-users in palliative care research? These discussions will be held in small groups i.e. one group will include both people having experience and having no experience. Afterwards, time will be scheduled for presenting the ideas back to the group.

**Abstract ID: 208**

**Abstract Type: Poster – COVID**

### Experiences among Swedish patients in specialized palliative home care and their significant others during the Covid-19 pandemic

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**Background:** Several Covid-related issues have so far been investigated. The threat from the pandemic for patients with progressive life-limiting illness and their significant others has not been studied.

There has been no formal lock-down in Sweden, but restrictions have been proposed and recommended, building on high confidence in the official authorities and personal responsibility. Our purpose was to explore experiences and consequences of the ongoing Covid-19 pandemic for patients in specialized palliative home care and their significant others.

**Method:** The study has a qualitative design based on interviews with patients and their significant others. The interviews were recorded, transcribed verbatim and analysed descriptively.

**Findings:** In total, 36 interviews were performed (of which 22 with patients). The findings disclose increased isolation and fewer social encounters due to the pandemic. The impact on personal life was described as ranging from very moderate to a torture-like experience. Some interviewees related the isolation more to decreased strength and functional decline due to the underlying condition than to the pandemic. Generally, the patients received necessary support in daily life thanks to efforts by their significant others and several creative solutions. However, the joy and support of meeting family and friends in real life were sorely lacking.

Anxiety and fear of being infected with Covid-19 were voiced. The significant others described frustration over not being able to provide the usual support. Both patients and significant others reported having received sufficient, and often crucial, support from the palliative care service during the pandemic.

**Conclusion:** The covid-19 pandemic affected patients and significant others in a range from moderate to torture like. They often found creative solutions to manage their everyday life. The goal of palliative care to provide appropriate support has generally been maintained during the pandemic.



**Abstract ID: 209**

**Abstract Type: Free Communication - Death literacy and knowledge of death systems**

**The Lancet Commission on the Value of Death: Bringing death back into life**

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

Yet at the same the relationship with death and dying in low- and middle-income countries is unbalanced with the rich receiving excessive care, while the poor, the majority, receive little or no attention or relief of suffering and have no access to opioids, as the Lancet Commission on Global Access to Palliative Care and Pain Relief showed. Excessive treatment for the rich and inadequate or absent care for the poor is a paradox and a failing of global health and solidarity.

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

The report intends to inspire a collective vision for the future. The recommendations outline the next steps for policy makers, health and social care systems, civil society and communities to take. This oral presentation will review the key components of the Commission report and discuss the recommendation and implications for practice and research.

**Abstract ID: 211**

**Abstract Type: Poster - ACP & End of Life communication**

**Development and evaluation of an in-hospital service to inform people about end of life rights: the SCEGLIERE service**

**De Panfilis Ludovica<sup>1</sup>, Perin Marta<sup>\*1,2</sup>, on behalf of the SCEGLIERE research group**

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**Background:** In 2018, the Italian law n.219 on informed consent and Advance Directives (AD) entered into force. Despite a positive attitude towards the Law's issues, a lack of information among citizen and health care professionals (HPs) hinders ADs' use in the country. The percentage of AD deposited is around 0,7%.

**Methods:** At the Local Health Authority of Reggio Emilia (Italy) a multidisciplinary service, labelled SEGLIERE (=choice), has been established to a) inform people on the rights guaranteed by Law n. 219, and to b) help people writing their AD. The implementation project comprehends several activities, from development to its evaluation.

**Results:** Firstly, we developed informative material on the Law n.219 and the service's characteristics with communication and health care literacy experts. Then, we organized the service, identifying appropriate locations, recruiting and training consultants, and defining procedures. 6 HPs working within the local health care facility (1 palliative care physician, 2 ethicists, 1 counsellor, 1 medical physician, 1 nurse) were recruited and auto-trained with 10 hours in role plays.

The service entered into force on May 4, 2021. The nurse is responsible for the first interaction with users, explaining the service's aim, collecting users' needs, and organizing meetings with 2 consultants.

The service received 18 requests: 14 appointments (but 1 cancellation) and 4 only telephone information.

To disseminate the service, we provided a training course targeting local HPs, to educate them

on Law 219 and AD's meaning. Between May 2021 and January 2022, 10 hours of training were provided, and 278 local HPs participated.

**Conclusion:** Our preliminary data show a significant interest from both citizens and HPs towards the service, but further activities are needed to increase its knowledge and accessibility. Moreover, the service will be qualitatively and quantitatively evaluated to understand the impact on clinical practice.

**Abstract ID: 213**

**Abstract Type: Poster - Equity and Access**

### Developing the competence of palliative care – project, multidisciplinary cooperation in long distance region

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**Background:** The need for palliative care increases as the population ages. Everyone has right to appropriate palliative care regardless of the place of residence. A report by the Ministry of Social Affairs and Health, recognizes regional differences in access to care and a lack of nursing competence in Finland.

Developing the competence of palliative care -project is conducted in cooperation between Kajaani University of Applied Sciences and Kainuu Social Welfare and Health Care Joint Authority. The aim is to describe and develop regional model for palliative care provision. In addition, to ensure palliative care competence of the social and health care staff in private and public sector, teaching staff and the third sector actors.

**Methods:** A survey on the competence needs of palliative care was launched. Workshops for private and public sector professionals was held. A palliative care network was initiated for public and private sector professionals in the region.

**Results:** Based on the results of the survey, a vocational palliative care training was implemented. Remote implementation of the palliative care training made it possible to participate from

region's distant areas. Assessment of the training submitted valuable information from competence needs in area. The nursing curriculum is developed based on results so education will be in line with the demands of working life.

Participants in the workshops was from home care, sheltered housing for older people and the disabled, emergency care and hospital at home. As a result, development goals of end-of-life home care were identified. Development of operating models continues with multidisciplinary actors in the spring -22.

The network of palliative care professional's supports flexible transfer of information, which improves the safety and quality of care.

**Conclusion:** The evaluation of the project is carried out based on the evaluation data of the participants. Further development takes place in a multidisciplinary collaboration with the inclusion of patients and near ones. The palliative care competence of working life representatives and educators will be strengthened. The project promotes access to equal and consistent palliative care for patients and their near ones in the Kainuu area.

**Abstract ID: 215**

**Abstract Type: Workshop**

### Take a crash course in using the Death Literacy Index

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**Objectives:** Death Literacy is defined as the knowledge and skills that people need to gain access to, understand, and make informed choices about end-of-life care options, and equip them to take action to support each other as they face death and grief. The Death Literacy Index (DLI) is a validated instrument that measures this capacity in groups of people in many settings, including communities and workplaces. Internationally, the DLI is used to start conversations and is applied in research and evaluation.

Participants will be introduced to the DLI; practice its use; work in small groups to understand death literacy in different settings; and use creative ideas to co-design strategies for increasing death literacy where they live and work.

**Interactivity:** This experiential workshop provides an interactive space for participants to practice using the DLI from various perspectives, whether community members, practitioners or policy makers. It is suited to people new to the DLI as well as those with some experience of its use. A maximum of 28 participants is set. All four facilitators have substantial knowledge of, and experience in the DLI, and are skilled enablers of engaging and interactive workshops.

**Learning Outcomes:** Upon completion of this workshop, participants will have a greater understanding of the DLI and its application, relevant to themselves, their communities or professional settings. Participants will be leave with ideas they have created on how to improve Death Literacy using this asset-based approach.

**Application to PHPCI:** People and communities with high levels of death literacy have context-specific knowledge about death systems and the ability to put that knowledge into practice. Compassionate Communities initiatives are an example of social interventions developed to enhance Death Literacy in line with Public Health approaches to dying, death and grief.

**Abstract ID: 216**

**Abstract Type: Poster - Family caregiving**

### **Concerns of the patients' relatives about Breaking Bad News to patients – An experience in a tertiary cancer centre in NE India**

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**Background:** In India, we have strong family ties. Every member of a family is important in decision making for the family. Whenever one of the family member gets ill, all other members come to know about the diagnosis first and they decide whether they want to divulge the truth to the patient or not. In most cases, the family members decide to hide it from the patient. According to medical ethics, patient has the right to know

about his disease and the status and our study is to find out the concerns of the family members about disclosing the diagnosis and disease status to patient.

**Materials and Methods:** The study was conducted in a tertiary cancer centre in North East India. Patients in the age group of 18 to 60 years, having cancer diagnosis but without any metabolic disease were selected. They were selected randomly during their first visit to the palliative care unit and relatives were informed about the study. Eligible and consenting relatives in the age group of 18 to 60 years were asked to answer a set of questions in the line of SPICE questionnaire.

**Results:** A total of 19 patients' relatives were interviewed. 13 out of 19 (68.4%) patients wanted to know the diagnosis. But 9 out of 19 relatives (47.4%) did not want to disclose the diagnosis. 10 out of 19 relatives (52.6%) wanted to disclose it citing various reasons like – patient has the right to know (20%), patient is capable enough to decide about the future (10%), better to give the right information rather than false hope (20%), patient has to undergo all the treatments by himself (30%) etc. Relatives do not want to disclose because – patient will psychologically break down (44.4%), may break hope and willpower (22.2%), may be harmful for the patient and the whole family (22.2%), patient want to live longer and do not want to discourage (33.3%) etc.

**Conclusions:** Several concerns expressed by relatives in disclosing the diagnosis to patients. It is important to talk to the relatives first to break the collusion. It is essential to tell the truth to the patient to maintain a good doctor and patient relationships.

**Abstract ID: 217**

**Abstract Type: Free Communication - Policy and Vision**

### **A Public Health hazard: if in jurisdictions permitting assisted dying (AD) palliative care (PC) rejects AD, all end of life care may suffer**

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**Background:** For International PC organisations, euthanasia and/or assisted suicide (EAS) are “incompatible with the very foundations of PC”. Yet, 300 million people worldwide now live in EAS-permissive jurisdictions and in many others EAS is on the societal agenda. In current or future EAS-permissive environments, PC organisations have three options: 1) keep excluding EAS from PC, 2) as in the Netherlands, leave involvement in EAS to individual caregivers who may act themselves or call in the Expertisecentrum Euthanasie, or 3) as in Belgium, embed EAS in PC.

**Aim:** To explore the public health issues raised by the controversial PC/EAS relationship.

**Methods:** Reviewing 1) the essentialist (epistemological, historical, doctrinal, conceptual, ethical) arguments to exclude EAS from PC. 2) the factual PC/EAS relationship in EAS-permissive jurisdictions.

**Results:** 1) Intellectually, several essentialist objections to PC accepting EAS are problematic. 2) Empirically, in Flanders (Belgium), EAS occurs three times more after a PC pathway than after non-specialised end-of-life (EOL) care. Together with in Oregon and Washington, over 70% of EAS are preceded by professional PC. In the Netherlands, there are no precise epidemiological data, but studies report that PC is usually associated with EAS cases.

**Conclusions:** 1) EAS seamlessly following conventional PC serves the continuity of care and the primacy of patient values. 2) Pragmatically, if in future EAS-permissive jurisdictions PC excludes EAS, EAS will be practiced only by caregivers who are likely less professionally competent for EOL care. Adverse consequences: 1) patients with EAS request may be nudged to shun professional PC and may thus not receive optimal EOL care and 2) EAS will likely be less practiced in a PC spirit of ‘total care’. Thus, the quality of all EOL care is likely to decline. 3) Further research is needed to explore if and how palliative care provision is affected by an E-Pas request.

**Abstract ID:** 218

**Abstract Type:** Poster – ACP & End of Life communication

**Support from health care professionals in empowering family carers to discuss Advance Care Planning: A population-based survey**

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**Background:** Family carers have a prominent role in end-of-life care for seriously ill persons. However, most of the Advance Care Planning (ACP) literature is focused on the role of health care professionals (HCPs).

**Aim:** To investigate what proportion of bereaved FCs has discussed ACP with their relative and to examine what proportion of these FCs received support from HCPs for these conversations, what type of support they did receive and whether they perceived the support as sufficient.

**Method:** Population-based cross-sectional survey of bereaved FCs of persons with a serious chronic illness (N=3000). The survey asked whether FCs had ACP conversations with their seriously ill relative in three months before bereavement, if and how they were supported by HCPs for these conversations and if they evaluated the support as sufficient.

**Results:** The response rate was 54.9%. The proportion of FCs that engaged in an ACP conversation with their relative was 46.9%. Of these FCs, 21.9% indicated they were not supported by any HCP to do ACP conversations. If supported by an HCP it was most often by a general practitioner (66.6%) and by doing the ACP conversation together (53.8%). The support was less often by explaining how FC could engage in ACP conversations themselves (17.9%) or by referring the FC to useful sources on ACP conversations



(9.4%). For 57.4% of the FCs, the support received by the HCP was deemed sufficient.

**Conclusion:** Our study provides a population-based estimate of the proportion of FCs that has ACP conversations with their seriously ill relatives. Our results indicate that HCPs supported FCs by performing the ACP conversation together. Empowering support by HCPs for FCs to perform ACP conversations themselves is rare. More insight in what FCs need in conducting these ACP conversations outside the clinical contacts is necessary.

**Abstract ID: 219**

**Abstract Type: Free Communication - Death literacy and knowledge of death systems**

### **Public Attitudes and Preparedness Toward Death: A Thematic Analysis**

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**Background:** Death is unpredictable but certain. Due to the Covid-19 pandemic, mortality becomes salient. Public anxiety towards death has been aroused internationally. But the death topic has not been widely discussed. The tendency to reduce anxiety is to understand death and preparation for death as it promotes a dignified death with self-control and own preference. In England, the public reported being comfortable in discussing this topic but they have not been translated into any specific conversations about their mortality and death planning.

**Objective:** To explore the attitudes of healthy middle-aged adults toward death and death preparation of own mortality.

**Design:** A qualitative interview employing vignette and semi-structured questions.

**Methods:** Seven British citizens aged 25-44 years were recruited. Each online interview lasted for about 45 minutes, was audio-taped, transcribed and analysed using Thematic Analysis.

**Results:** Six overarching themes were identified. The respondents presented affective-cognitive

ambivalence towards death. They showed complex emotions toward their mortality and negative perceptions toward dying despite being comfortable talking about death in general. The negative reactions were influenced by their expectations and dying preferences. Nevertheless, the respondents gain insights on the awakened life upon reflection on death. Moreover, they tried to overcome death by adopting fantasy thoughts of changing and mechanisms that signified immortality. On the other hand, the importance and advantages of death preparation, such as an assurance of a dignified death and a sense of relief were acknowledged by the respondents. However, the preparation engagement remains low due to readiness factors.

**Conclusion:** The current study indicated that healthy middle-aged adults had attitudinal ambivalence towards death and death preparation. Implications on death education, death literacy framework and positivity of death in health context were discussed.

**Abstract ID: 220**

**Abstract Type: Free Communication - Culture, philosophy and spirituality**

### **Compassion and hope: Bridging public health and hospice care**

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Hospice care has always aimed to overcome boundaries, for instance between care provided at home and care provided at an institution, or between care provided by volunteers and care provided by professionals. In this presentation, the two presenters - an palliative care physician and a chaplain; both scientists as well - make clear, based on their own studies and those of others, that compassion and hope have always been part of this 'bridging' function, in person centred hospice care as well as a public health approach of palliative care. They will describe the 'relational ethics of hope,' in which patients, their loved ones and health care professionals balance empowerment (hope) and compassion (struggle). They will present how compassionate communities can be (come) communities of hope, and how these communities bridge care provided at home, at a hospice, at an institute et cetera. They will also show

how hope and compassion, which are central in spiritual care in palliative care, are excellent ways of providing spiritual care as a multidisciplinary team, including volunteers

**Abstract ID: 221**

**Abstract Type: Free Communication - Death literacy and knowledge of death systems**

**Factors influencing death literacy in a Swedish sample**

*Therese Johansson*<sup>\*1</sup>; *Carol Tishelman*<sup>2,3</sup>; *Lars E. Eriksson*<sup>1,4,5</sup>; *Joachim Cohen*<sup>6†</sup> & *Ida Goliath*<sup>1,7†</sup>

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**Background:** Community capacity for end of life (EOL) issues has recently been conceptualized as death literacy (DL), encompassing a set of knowledge and skills needed to engage in EOL-related situations. This study aimed to explore how sociodemographic, health, and experience-based factors are associated with DL, as measured by the Swedish-language Death Literacy Index (DLI-S).

**Methods:** Cross-sectional data were collected online from a quota sample ( $n = 503$ ), aged 18–86 ( $\bar{x} = 49.95$ ,  $SD = 17.92$ ), recruited from an existing national survey panel. Bivariate correlations between predictors and DL were analyzed using linear regression. From a causal diagram a 3-step hierarchical regression model was created.

**Results:** Overall, the regression model explained 34.8% of the variance in DL,  $F(16, 486) = 16.22$ ,  $p < .001$ . In step 1, three factors accounted for 9% of the variance: being widowed ( $b = 1.87$ ,  $p < .001$ ), older age ( $b = 0.02$ ,  $p = .006$ ), and having a religious belief ( $b = 0.64$ ,  $p = .004$ ). Adding professional care background in Step 2 contributed to an additional 16% of variance, as having worked in health care ( $b = 1.18$ ,  $p < .001$ ) was a strong predictor of DL. Inserting experience-based factors in step 3 explained another 9.9% of the variance, as experience of EOL care provision ( $b = 0.77$ ,  $p = .002$ ), grief support provision ( $b = 0.96$ ,  $p < .001$ ), and supporting someone with life-threatening

illness ( $b = 0.75$ ,  $p < .001$ ) all significantly predicted DL. In this presentation we will address potential causal pathways between factors and DL.

**Conclusion:** This study is, to our knowledge, the first to examine and model individual, relative, and collective influence of different factors on DL. Our findings confirm the original DLI developers proposed model in the Swedish context. Though the key role of EOL experiences for DL was highlighted, the moderate degree of overall variance explained suggests that further research is needed to better understand how preparedness for EOL care can be strengthened in the community.

**Abstract ID: 222**

**Abstract Type: Workshop**

**Participatory workshop on the Death Literacy Index: Examination and reflection about its cross-cultural relevance and viability**

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There is growing global interest in public health approaches in palliative care (PHPC) that promote individual and community capacity-building for end of life (EOL) care, dying, death, and loss. Such EOL capacity can be conceptualized as death literacy, a multi-dimensional construct that the Australian Death Literacy Index (DLI) measures on a group-level. As such, a DLI version that is both relevant and comparable across languages and countries can be useful to evaluate PHPC initiatives and assess EOL preparedness.

In this workshop, we aim to stimulate discussion about both potentials and challenges in translating and adapting the DLI related to e.g. linguistic,

cultural and health care system differences, and how these might affect the viability of the instrument in different contexts. No prior familiarity with death literacy or the DLI is needed.

We will briefly present the DLI and share examples of experiences from translation, adaptation, and validation processes in an international study, conducted in Sweden, Belgium, and the Netherlands. The workshop continues with small interactive group discussions, progressing into a general discussion facilitated and documented by members of the workshop team. This workshop is expected to generate suggestions for optimizing the DLI for future national and international research. Workshop insights will be summarized and shared with all participants after the conference.

This workshop builds on principles of knowledge exchange, enabling mutual learning for all participants. Expected learning outcomes are:

- Linguistic, cultural, socio-political, organizational, and other contextual differences to consider in relation to DLI adaptation and translation, and how these might affect the relevance of the DLI overall or specific items
- Suggestions for revising the DLI to make it more cross-culturally viable, while recognizing the need for context-specificity
- Pros and cons of attempting to develop generic vs country-specific versions of the DLI

**Abstract ID: 223**

**Abstract Type: Free Communication - Community ACP**

### **Dissemination, Use and Impact of a Community-based Advance Care Planning Intervention: Ripple Effects of the Swedish DöBra cards**

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**Background:** There is growing interest in community-based advance care planning (ACP) interventions, but few studies investigate the societal impact of such initiatives. A Swedish adaptation of the GoWish cards, the DöBra cards, were

used as a tool in the SweACP participatory action research project with older people in the community, without imminent End-of-Life (EoL) care needs. Due to popular demand, the DöBra cards were later made available to the general public as a social innovation.

**Aim:** To explore how the publicly available DöBra cards have been disseminated and used without researchers' engagement, to provide a basis for understanding their impact in a wider community setting.

**Methods:** Using a Ripple Effects Mapping approach, we followed three chains of dissemination of the DöBra cards originating from a patient organization, a national interest organization for older people, and a health care organization. Data were collected through interviews with 20 participants and analyzed with directed content analysis.

**Results:** A variety of strategies for use were noted, as the DöBra cards were adapted to fit needs in different personal, professional, and organizational settings. The cards were found to act as both a means to raise awareness about EoL issues in different contexts, as well as an end in themselves, e.g. by facilitating ACP conversations for people with serious disease. However, in some instances, resistance to use or promotion of the DöBra cards was also described. Impact included personal development as well as strengthened personal and professional relationships, with potential to affect EoL care provision.

**Conclusions:** The primarily positive perspectives and broad dissemination of the DöBra cards in a variety of contexts beyond those controlled by researchers, has led to capacity building in dealing with EoL issues in the community, as the topic of dying and death has been brought to agendas in new contexts.

**Abstract ID: 224**

**Abstract Type: Free Communication: Loss and grief**

### **Guideline-based end-of life and Bereavement Support for families in cancer CARE (BEST CARE): An implementation research study**

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**Background:** Terminal cancer and the subsequent loss of a close other is a stressful, incisive experience that significantly impacts family members' physical and mental health. However, best practice recommendations for family engagement (FE) and support during end-of-life (EoL) and in bereavement are often not consistently adopted in cancer care across acute and community-based settings in Switzerland.

**Aim:** This implementation research study investigates the current adoption and contextual determinants of EoL and bereavement support to families of cancer patients.

**Methods:** An online survey using RedCap© is currently underway in 4 acute and 3 community-based cancer care services, with a target sample size of 200 cancer care professionals. Study endpoints include the level of adoption of guideline-based engagement and support practices, and contextual determinants at the individual (i.e., knowledge, skills, attitudes, role understanding) and the organizational level (i.e., financial incentive, resources, leadership culture, barriers). Linear regression analyses will be conducted to determine the influence of contextual determinants on adoption of best practice recommendations.

**Results:** Findings will be presented according to the cancer care setting and type of professional group. Findings on the current adoption level and most influential individual and organizational determinants will portray areas for future improvement and implementation activities.

**Conclusion:** The BEST CARE study will contribute knowledge on barriers to and extent of adoption of EoL and bereavement support to families of patients with cancer, which is needed to improve evidence-based health service delivery. Investigating the care context and factors that determine uptake of FE and support enables to develop implementation strategies of family-focused care at the EoL and in bereavement that are tailored to the identified barriers and enablers in each service context in a participatory manner.

**Abstract ID:** 226

**Abstract Type:** Symposium

**Strategies to create awareness and engage the public in preparing for the end of life. Examples from the Netherlands**

*H. Roeline Pasman*<sup>\*1</sup> (chair), *Natasja J.H. Raijmaker*<sup>2</sup> (chair), *Larissa Exalto*<sup>3</sup> (speaker), *Gudule Boland*<sup>4</sup> (speaker), *Rob Bruntink*<sup>5</sup> (speaker), *Annicka van der Plas*<sup>1</sup> (speaker)

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Public knowledge about end-of-life care is suboptimal. From a representative Dutch older adult panel, a quarter stated that they had never heard of the term palliative care or only knew this term, but not what it entails. Moreover, about a quarter stated 'don't know' on statements about palliative care, such as "palliative care is only for people that have a few weeks to live" and "palliative care is for patients with cancer only". For people with lower education these percentages were higher. Knowledge about palliative care, what choices there are, and what care is available is important to create awareness and stimulate people to prepare for their end of life. This symposium aims to present strategies for creating public awareness about the end of life. It will consist of 4 presentations followed by discussion.

- 1) A Public awareness campaign: The website Overpalliatievezorg.nl wants to guide people on what palliative care is and how it can contribute to their quality of life. Several marketing and communication strategies are used with the aim that patients and their relatives find the information they need.
- 2) Discussing palliative care in plain language: Pharos will present their communication training for healthcare professionals, films to promote talking about end-of-life care (in four languages) and plain language patient leaflets to explain aspects of palliative care to people with limited health literacy.
- 3) Tools for public awareness about the end of life: Bureau MORBidee will present



their experience with social media campaigns ('Let's talk about death'), beer mats, conversation starters, card games, a mobile Before I Die Wall (chalk board), Death Cafes and a yearly Mortality Day (first day of autumn).

- 4) Information meetings about the end of life: Amsterdam UMC will present a toolkit for healthcare professionals to organise meetings for their patients/the general public, and how these meetings influence readiness to start preparing for their end of life.

#### Abstract ID: 227

#### Abstract Type: Poster - Paediatric Palliative Care

#### Beyond bricks and mortar: enabling equity of access to paediatric hospice care for Queensland children and families

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**Background:** Hummingbird House (HH), Queensland's only children's hospice, based in Brisbane, Queensland, Australia, offers care to children with a life limiting condition (LLC) and their families in the form of short break stays, emergency respite, end of life, post death and bereavement care. From the outset, HH had a vision for state-wide care, now at 5 years old, with the hospice building/service established, there is capacity to explore what resourcing and embedding a state-wide model of care could look like. A new vision statement affirms this ambition Every family in Queensland is connected to a community that knows how to care for them in life, death and bereavement. Work is now underway on a Regional Development Strategy (RDS) aligned with a Compassionate Communities (CC) and public health model of palliative care (PC) paradigm. This 'out of the box' abstract presents an emerging RDS and invites dialogue from conference delegates around how these models, more common in adult PC, can be translated into the paediatric context.

**Methods:** Data to support development of the RDS was collated through 1. A Rapid Literature Review, 2. A desktop service mapping exercise, 3. Community consultation with Australian and international colleagues.

**Results:** There is a growing body of evidence that supports the extension of adult hospice care beyond 'bricks and mortar' into regional communities. Link centres, community connectors, community development outreach workers are some examples. However, there is a paucity of data and/or service frameworks within the paediatric hospice sector that adopts a similar approach to care.

**Conclusion:** This presentation is a 'call to action' exploring how public health and CC approaches to palliative care can translate into the paediatric hospice sector. The authors pose a question to delegates: How can an intergenerational public health and CC approach enable equity of access to hospice care for children and families currently isolated by geography?

#### Abstract ID: 228

#### Abstract Type: Symposium

#### Making serious illness, death, dying and loss 'part of life' in educational institutions

*Sarah Dury*<sup>\*1</sup> (chair), *Sally Paul*<sup>2</sup> (speaker),  
*Marieke Groot*<sup>3</sup> (speaker), *Veerle Coupez*<sup>4</sup>,  
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Compassionate Communities have been put forward as a new model for community-based palliative care to positively impact the health and wellbeing of those experiencing the challenges of serious illness, death, dying, and loss. The literature indicates that especially educational institutions might play an important role in integrating experiences of serious illness, death, dying and loss in local communities. Educational institutions are at the same time learning environments, intergenerational hubs, employers, and formative actors that can create safe spaces, where these topics are not taboo topics, but can be discussed.

This symposium wants to explore the role of educational institutions in fostering compassion and brings together different educational institutions that are at various stages of developing compassionate initiatives within an educational context. The symposium will share experiences about the development process, the challenges and successes and promote further advances.

Sally Paul will start by discussing the role of education communities in public health palliative care. Drawing on her research with school communities she will present a conceptual model for compassionate schools and how this links with public health palliative care education. Marieke Groot follows with their specific living lab in the Netherlands and focuses on the methods, current situation and first results of the route towards a Compassionate University College. Veerle Coupez en Greetje Desnerck explain how an informal group of ‘believers’ of Howest (UAS Flanders) developed a Compassionate school. They give an insight in the learning network with the VUB and the services of student support. Hanne Bakelants closes the symposium with her research on the development of a Compassionate University in Belgium – Vrije Universiteit Brussel. The goal is to understand how different stakeholders build a shared understanding of the aims and objectives of the Compassionate University and how community members experience the development process.

**Abstract ID: 229**

**Abstract Type: Poster - Family caregivers**

### Experiences of parenthood when a parent has been diagnosed with ALS

*Nina Malmström<sup>1</sup>, Joakim Öhlén<sup>1,2,3</sup>, Stefan Nilsson<sup>1,2</sup>, Birgitta Jakobsson Larsson<sup>4</sup>, Ingela Nygren<sup>5</sup> and Anneli Ozanne<sup>\*1,6</sup>*

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**Background:** Amyotrophic lateral sclerosis (ALS) is a neuromuscular progressive disease that attacks the nerve cells in the brain and the spinal cord that control movements of the muscles. This leads to muscle wasting and paralysis of, among other things, extremities, speech, swallowing and

breathing muscles. The average survival is 2-5 years from the first symptoms. The disease means that the person increasingly needs help, and the family is often involved in that support. Research focusing on the parent perspective based on the experiences of both the ill and the healthy parent is limited. Therefore, the aim of this study is to explore the meanings of parenthood when one of the parents has been diagnosed with ALS.

**Methods:** Parents who have been diagnosed with ALS and their partner, or former partner, with whom they have children in common were interviewed separately. To date, 13 interviews with ill parents and 12 interviews with healthy parents have been conducted. 13 participants were women, and 12 were men. The interviews lasted about an hour, were audio recorded and transcribed. Phenomenological hermeneutic approach to the analysis is ongoing.

**Results:** The preliminary results show that both the ill and the healthy parents are very worried about the children’s situation. They are aware that the children take a great responsibility, and they are afraid that it prevents the children from living their own lives and spending time with friends as they otherwise would have done. They related about difficulties to talk to each other in the family, which create a culture of silence and the parents sometimes “protect” the children by excluding them from knowledge and support from the healthcare.

**Conclusion:** The results will lead to an increased knowledge of both the ill and the healthy parents’ situation. It will provide information that will be clinically useful in conversations with the whole family as well as in future supportive actions aimed at this target group.

**Abstract ID: 230**

**Abstract Type: Free Communication - Community engagement and development**

### Designing human-centred palliative environments

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**Background:** The palliative environment (PE) can influence various users’ experiences of palliative care. Hence, architects could incorporate

human-centred recommendations into their designs of PE to support such users (i.e., patient, family, caregiver, volunteer) in multiple dimensions of their wellbeing (i.e., physical, emotional, social, and spiritual). However, the impact of research in this field on architectural practices seems little so far. Architects seem to be hampered in using evidence-based knowledge to design PE because the research is usually considered difficult to access, rarely targeted at architects, and challenging to integrate into design. In such cases, architects usually use their intuitive knowledge. However, since PE are generally not commonplace buildings, a possible discrepancy between architectural practice and users' needs and wishes can occur. To increase the impact in practice, it is necessary to consider which and how 'spatial aspects' affect users' experiences and wellbeing with(in) PE.

**Method:** A scoping review on users' experiences and wellbeing with(in) PE was performed to define spatial aspects; but, from an architectural perspective, some aspects were still missing. Performing fieldwork as a volunteer in two PE enabled data collection through qualitative methods (i.e., participant observation, case study analysis, and photo-elicitation interviews).

**Results/conclusion:** Users' experiences in PE can differ quite extensively, yet research in this field rarely takes a multi-user perspective. In our project, we explore the impact and interconnections of spatial aspects on users' experiences and wellbeing in PE while integrating multiple users' voices. Knowledge of these various users' experiences was linked to spatial aspects and then categorised into five main themes. These results provide insights, ideas, and support for (re) designing and researching human-centred palliative environments.

**Abstract ID: 231**

**Abstract Type: Free Communication - Arts and end of life**

### **Imaginative Communication Across the Borders of Death. End-of-Life Narratives in Palliative and Bereavement Care**

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**Background:** In 2021, dying mother Lara Switten left a book with stories and pictures to her children. Lara's so-called end-of-life (EOL) narrative, created with the support of biographer Ine Nijs, attests to a growing trend of storytelling practices in Western-European palliative EOL care that prompt us to rethink the modified ways in which the dying anticipate death. More and more people facing severe illness are supported by caregivers and external biographers (e.g., Amfora, Flanders; Passeurs de mots, France) to review their lives and to pass down these stories to loved ones. Research has emphasized the therapeutic benefits of narrative life-review for the dying, relatives, and caregivers in EOL stages. Little is known about the implications of EOL narratives for the bereaved.

**Methods:** Previewing my literary-sociological study on EOL narratives as textual results of these cultural practices, I address this challenge from the perspective of literary studies and assume an imaginary communicative loop, in which the dying and the bereaved are engaged as authors-narrators and readers-recipients. By comparing Lara's EOL narrative with Ley's fictional 'For when I'm gone' (2020), I argue that literary techniques, such as imaginative narration, structure the ways in which the dying want to be remembered and how they anticipate a future of which they will no longer be part. I hypothesize that the dying and the bereaved not only attribute meaning to EOL narratives in terms of a continuation of parental and intimate roles in absentia. EOL narratives likewise elicit disrupting experiences and intergenerational incomprehension.

**Conclusion:** Insights into how literary techniques and narrative scripts modify the communicational character of EOL narratives will enhance our understanding of how these texts help the bereaved imagine the deceased and how their relationship could have looked like, and will lead to evidence-based guidance for those involved in narrative practices in EOL care.

**Abstract ID: 232**

**Abstract Type: Poster – COVID**

### **Impact of Covid Pandemic on ambulatory palliative care**

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**Background:** The COVID-19 pandemic has a dramatic impact on the whole continuum of patient care. Respective data from the palliative care setting are scarce. Our aim was to compare diagnosis profile, stage of disease at admission and outcome in an ambulatory palliative care setting before and during the pandemic.

**Methods:** We studied a cohort of consecutive patients admitted to an ambulatory palliative care provider in Saxony, Germany, during a 21-month time period before the pandemic, between March 2018 and November 2019, with a cohort of consecutive patients admitted in a comparable 21-month time interval during the ongoing pandemic, between March 2020 and November 2021. We compared number of admissions, diagnosis profile (oncologic/non-oncologic main diagnosis), time under palliative care and place of death.

**Results:** The number of admitted patients was similar during the two periods: in total, 1,335 patients were admitted during the pre-pandemic interval compared with 1,345 patients in the pandemic. The diagnosis profile did not differ: pre-pandemic, 1,096 patients (82.1%) had malignancy as main diagnosis compared with 1,117 (83.0%) during the pandemic ( $p=0.52$ ). Time remaining under palliative care was somewhat longer during the pandemic: pre-pandemic, 722 patients (53.7%) up to 28 days and 623 (46.3%) more than 29 days compared with 688 patients (49.9%) and 691 (50.1%) during the pandemic, respectively ( $p=0.048$ ). There was a statistically significant difference in place on death: 246 patients (18.2%) died in a nursing home in the pre-pandemic cohort compared with 205 (15.0%) during the pandemic.

**Conclusions:** Malignancies were the main diagnosis in patients admitted in palliative care in the large majority both before and during the pandemic. The percentage of patients exceeding 4 weeks in palliative care was higher during the pandemic while the number of patients dying in a nursing home facility decreased. Despite statistical significance, differences were moderate.

**Abstract ID:** 233

**Abstract Type:** Free Communication:  
Family caregiving

**Being a child of a parent diagnosed with ALS  
- from the child's perspective**

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**Background:** Support can be both challenging and needed for children when a parent is ill with a life limiting condition. Amyotrophic lateral sclerosis (ALS) is a neuromuscular progressive disease that attacks the motor nerve cells in the brain and the spinal cord that control movements of the muscles, which leads to muscle wasting and paralysis. The average survival is 2-5 years from the first symptoms. The ill person increasingly needs help and the children may be involved in that support, while they witness how their parent deteriorates and eventually dies. Research focusing on children is limited, in particular from a first person perspective; voices of the children themselves. Therefore, the aim of this study is to explore the meanings of living as a child with a parent who has been diagnosed with ALS.

**Methods:** To date, 10 individual interviews of children between the ages of 13 and 25, who fully or partially live together with the ill parent, have been conducted. The interviews lasted about an hour, were audio recorded and transcribed. Phenomenological hermeneutic approach to the analysis is ongoing.

**Results:** The preliminary results show that the children are in a very vulnerable situation, especially if the parent has a severe bodily disability and personal assistance or other health-care professionals working at home. The children take great responsibility in both supporting practically at home and helping the ill parent. At the same time, they experience that their own lives are limited. Witnessing how the parent becomes increasingly deteriorating create feelings of fear and there is a great uncertainty about the future. The children try to protect their parents by avoiding talking about their own emotions and how the disease context affects themselves.

**Conclusion:** The results will lead to an increased knowledge of the children's situation, which is of great importance for future supportive action



aimed at this target group to promote or maintain their health.

**Abstract ID: 235**

**Abstract Type: Poster - ACP & End of Life communication**

**Advance Care Planning in Italian palliative care networks: a grounded theory study**

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**Background:** The Italian law n. 219/2017 on informed consent and advance directives regulates also Advance care Planning (ACP) (Article 5). Despite the great acknowledgment of the law, several difficulties persist among palliative health care professionals (HPs) in ACP implementation. This study aims to understand if and how palliative HPs involve their patients in the decision-making process.

**Methods:** We adopted the Grounded Theory method, following a constructivist approach. We conducted semi-structured interviews with an initial sample unit of palliative care specialists, their patients, and caregivers. Participants were recruited from two local palliative networks working in the Emilia Romagna region (Italy).

**Provisional Results:** So far, we have performed 19 interviews. Participants were 13 palliative care specialists, 4 patients, and 2 caregivers. We identified 14 initial conceptual categories organized into a provisional conceptual model through open and first focused coding, describing ACP as mainly an informative process among specialists and patients/caregivers. Involving patients was within a trust relationship between physicians and patients, making them feel they had an 'inevitable choice.' Sharing values with patients and their relatives facilitated physicians to discuss crucial choices with them, mainly the end-of-life ones. In contrast, patients' lack of awareness, impaired cognitive capacity, and conflicting value perspectives complicated or, at times, hindered ACP. Further investigation is needed to understand

how physicians, patients, and caregivers deal with contradictory situations and its implication for ACP.

**Conclusion:** The study is currently ongoing. Our results shall represent the basis for developing local guidelines to support HPs in implementing ACP. The final results will be presented at the congress.

**Abstract ID: 242**

**Abstract Type: Free Communication - Equity and Access**

**Homeless Outreach and Palliative Care Education (HOPE) Pilot Service**

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**Background:** Prior to the Covid 19 pandemic some shared learning had taken place between Mary Stevens Hospice their local hostel and members of the police force following a series of events surrounding the death of a homeless man. This was an event that was shared at PHPCI 2019. Following receipt of successful funding the HOPE 2-year pilot programme commenced in January 2022.

The programme adopts a 3 tiered approach which will incorporate education, an outreach service and the award winning No Barriers Here, which uses an arts based approach to advance care planning.

**Method:** The initial tier of the project is the development of an eight-education session rolling programme to be delivered twice yearly. The aim of the education is to facilitate the development of third sector staffs' knowledge, enabling them to identify, and support people who are experiencing homelessness, with advanced ill health, and may be experiencing palliative and end of life care needs.

The second tier is the development of an outreach hub where people who are experiencing homelessness or structural vulnerability will have timely access to palliative care including bereavement support. It also includes support for third sector staff supporting this vulnerable population in signposting to the appropriate services.

This outreach work is being developed in partnership with the local Integrated Health Care Trust.

The last tier of the project will focus on increasing the number of people experiencing homelessness who are given the opportunity to make informed choices and decisions about their future care.

**Results:** It is hoped that the results from this project will inform the development of pathways into hospice services; will encourage the development of a community of practice within the locality and will facilitate a palliative care and homeless network.

The early findings will be available late 2022.

**Conclusion:** This project seeks to improve access to palliative care by populations who are experiencing homelessness through education and outreach support.

**Abstract ID: 243**

**Abstract Type: Free Communication - Family caregiving**

**Informal care in times of COVID-19: Lived experiences of informal carers in Belgium**

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Informal carers often remain invisible to policy makers, professional caregivers, and the academic world. However, in Europe 80 percent of long-term care is provided by informal carers. When the COVID-19 epidemic took hold of the world, they were therefore disproportionately affected by the restrictions and consequences of COVID-19. HOGENT and Steunpunt Mantelzorg conducted research on the experiences of informal carers in Belgium during this period, to acquire more data, to formulate recommendations for policymakers, and to provide adequate support to informal carers as an organisation.

In this workshop we go over the most important research results and our policy recommendations. We bring forward the lived experiences of informal carers through testimonies, in which they explain the consequences of COVID-19 and informal care on their lives. Furthermore, we explain what we have done with the

policy recommendations as an organisation that supports informal carers, and what the current needs and challenges are of Belgian carers. Participants of the workshop will be offered insight in some of the methodologies and activities that our organisation uses to inform and empower informal carers.

**Abstract ID: 245**

**Abstract Type: Free Communication - Compassionate cities**

**Development and Implementation of Compassionate Communities in Japan: approaches initiated by a home hospice clinic**

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Despite the huge potential needs for improvement of end of life (EoL) care, the awareness of the needs and the capacity to provide good EoL care in the community are insufficient. Rapid population aging in Japan has been widening this gap, which could result in deterioration of the quality of EoL care. Therefore, we have been developing approaches to empower the community for the provision of better EoL care through our GP practice including home hospice care.

Since the establishment of our clinic 25 years ago, we have been striving to provide more than medicine itself, thinking what we can do for every life in the community to achieve better quality of our EoL care. Our effort includes; giving lectures at schools and local community centers to raise awareness about better EoL care; organizing bereaved member groups to facilitate peer support care; establishment of home hospice volunteer group, providing education for the applicants and working with them after they registered. Along with over a thousand of EoL care, our efforts gradually have been spreading into the community. Quite a few bereaved members who has experienced home hospice care with us are now playing an important role providing compassionate EoL care as volunteer members. Besides, trained volunteer members have launched new volunteer groups in each of their living area and working with their communities. In this way, our community-based home hospice care has been building capacity of the community to embrace life with compassionate EoL care.

In this presentation, we will share how we have developed and implemented our sustainable compassionate communities in Fukuoka, Japan.

**Abstract ID: 248**

**Abstract Type: Poster - Health Promotion**

**Promoting the health and wellbeing of family caregivers providing end-of-life care – the role of community Healthcare Assistant**

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**Background:** Healthcare Assistants (HCAs) are recognized as providing the majority of patient care and often are the closest point of contact for patients and family caregivers across the disease trajectory, including end of life. Their contribution to minimizing the impact of illness, promotion of health and helping family caregivers' function at home has the potential to be invaluable. However, little is known about their role and preparation during this time. As part of a larger investigation into HCA lone working, this paper examines the role of the HCAs in public health promotion to family caregivers at the end of life.

**Methods:** An exploratory study comprising semi-structured interviews with Marie Curie lone working Health Care Assistants providing palliative care in the community, mostly during the out-of-hours period. Data were analysed using thematic analysis.

**Results:** Findings indicate that HCAs play a pivotal role in promoting health by encouraging, educating and empowering family caregivers to make positive choices for themselves in relation to health and wellbeing, whilst they adapt to and accept dying. A vital part of the HCA role was providing emotional support to family caregivers, and a safe environment in which caregivers could disclose their experiences of burden and anticipatory grief, helping them to prepare and plan for their future. The HCAs presence and readiness to engage in difficult conversations, provided a platform for caregivers to share their fears, and vital opportunities for HCAs to assess caregiver needs and signpost them to relevant services and community resources.

**Conclusion:** While further research is required to explore the impact of HCAs' role on the family caregivers' quality of life and capacity to cope, this research suggests the role has potential for providing meaningful public health interventions. HCAs have a unique opportunity to promote self-care and engagement in healthy behaviours to reduce the emotional and physical impact of the family caregivers' role.

**Abstract ID: 250**

**Abstract Type: Free Communication - Equity and Access**

**Research and action to support care for serious illness in inner city settings**

*Kelli Stajduhar\*<sup>1,2</sup>, Ashley Mollison<sup>1</sup>, Kara Whitlock<sup>1</sup>, Annie Do<sup>3</sup>, Piotr Burek<sup>4</sup>, Robyn Kyle<sup>5</sup>*

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**Background:** Drug poisoning, discrimination, racism, and health inequities contribute to early and preventable deaths in inner city settings. Serious illnesses, such as cancer and organ failure, are exacerbated by barriers to health and social care. People who work in inner city settings often become caregivers for people experiencing serious illness, but are unrecognized and unsupported in this work.

**Methods:** Over a 2-year period, interviews, observational field notes, and participatory action cycles (18 meetings) were conducted with a group of 15 health care, housing, shelter, outreach, and peer workers. In addition, iterative action cycles resulted in 12 community-based interventions to demonstrate impact. Data were recorded, transcribed, subjected to thematic analysis, then synthesized into a toolkit.

**Results:** A toolkit was created in partnership with inner city workers to improve the support they receive during and after caring for people with serious illness. Rather than asking workers to do more within their existing role, this toolkit reorients the work they are already doing as a valuable contribution to the care of people with serious illness. Comprised of seven chapters and supplemental resources, the toolkit offers information on how to identify and obtain supports for people with serious illness, what to

expect as people's health declines, natural prompts for end-of-life conversations and decision-making, and individual and collective responses to grief and loss. The toolkit is offered in electronic, printable, and verbal formats; accompanied by videos, handouts, and presentations, which will be made available to conference attendees.

**Conclusion:** Expanding civic and social responsibility for death, dying, and grieving necessitates research and action with people typically excluded from public health and other health and social systems. Rather than 'imparting' professionalized knowledge in inner city settings, this project builds on existing strengths, knowledge and experiences of people doing this work.

**Abstract ID: 251**

**Abstract Type: Workshop**

**Compassionate Workplaces: a workshop exploring how workplaces can become compassionate communities**

*Deborah De Moortel*<sup>\*1,2</sup>, *Sara De Gieter*<sup>1,3</sup>, *Steven Vanderstichelen*<sup>1,4</sup>

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Compassionate communities intend to create more aware networks around the persons experiencing death, dying and loss. A compassionate workplace is a specific form of a compassionate community that tries to build a network for workers experiencing death, dying and loss. Very often working partners, children, or parents take care of family members with serious illnesses at the end of their life, and are forced to juggle work and care responsibilities. The combination of care responsibilities, experiences of loss and bereavement and the difficult exercise of balancing work and family roles can lead to stress, and even absenteeism. A compassionate workplace hopes to accommodate the needs of these workers by (1) decreasing the stigma around bereavement and loss at the workplace (e.g., by providing a specific room for bereavement); (2) building networks of support in the workplace (e.g., reorganizing the work tasks, getting help and support from co-workers); and (3) enhancing the capacities for dealing with death, dying and

loss of family caregivers who are working (e.g., accommodating to the personal needs of the worker-care taker). Yet, compassionate workplaces are a relatively new concept, so how to create them in practice is underexplored. This workshop intends to explore the concept of compassionate workplaces from an international end-user perspective by gathering expert opinions from community members, employers, employees, researchers, etc. We first present what is currently known about compassionate workplaces, offering examples from research and practice. Subsequently, we will hold several 20 minute brainstorm discussions (groups of max 5 participants) on each of the following topics:

- Mourning at work (e.g., What can a compassionate workplace do for decreasing the stigma around death, dying, and loss?);
- Accommodating worker-care takers (e.g., What workplace practices can protect the health and well-being of these workers?);
- Compassionate workplaces for precarious and other vulnerable workers (e.g., Do practices of compassionate workplaces reach all workers?);

Each group will have a facilitator to take notes and summarize for the group in a final plenary discussion. Proceedings from the workshop will be shared with all participants to keep the debate going past the conference.

**Abstract ID: 252**

**Abstract Type: Free Communication - Family caregiving**

**Expanding the circle for who can care: Challenging nuclear family dominance in care, dying, and bereavement**

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**Background:** Demographic trends toward smaller family sizes, greater distances between family members, and families that deviate from the nuclear structure are changing how care is received and provided in the West. People with serious illness are increasingly reliant on those beyond biological and legal relations. Yet, normative assumptions about family and caregiving



embedded in legislation and policy continue to locate, prioritize, and privilege the nuclear family as the site of care. The nuclear family ideal has implications for Public Health Palliative Care (PHPC) movements seeking to democratize care, dying, and grieving.

**Methods:** Drawing from interdisciplinary fields (e.g., family gerontology, sociology, health equity, palliative and end-of-life care), practice examples from personal experiences, and community-based research, this presentation interrogates dominant notions of family and caregiving, unpacking their relevance for PHPC movements.

**Findings:** Canadian research with people experiencing social and structural inequities offers insights into challenges and opportunities for PHPC movements. Despite efforts to expand civic responsibility for death and dying, ideology and social organization continue to shape who is cared about, who does the caring, and how. By showing the value of care for serious illness outside the nuclear family (e.g., workplaces, schools, churches), PHPC movements have the potential to make explicit non-normative conceptualizations of family and caregiving. These efforts can improve the experiences of both people who are dying and their ‘chosen’ caregivers and create more equitable care by broadening the circle of who can care and grieve.

**Conclusion:** PHPC movements can challenge assumptions built into notions of family and caregiving to improve experiences of people with serious illness and their supporters – both inside and outside the health care system.

**Abstract ID:** 253

**Abstract Type:** Free Communication - Health Promoting Palliative Care

### **Palliative Care Awareness Week 2021 - A Collaborative Approach to a public information campaign**

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**Background:** All Ireland Institute of Hospice and Palliative Care (AIIHPC) held its eighth annual Palliative Care Week Awareness campaign in September 2021, themed: “Palliative Care: It’s more than you think.” Established in

2014, the campaign aims to increase awareness and understanding, and challenge public perceptions of palliative care, through a collaborative approach.

**Methods:** As facilitator of Palliative Care Week, AIIHPC collaborated on and supported events and activities planned by its partners and key stakeholders in the palliative care and wider health sector for Palliative Care Week.

A Palliative Care Week Reference Group with 85 members was established with 26 AIIHPC partner organisations, Voices4Care Members (AIIHPC’s voluntary panel of people with palliative care needs, carers and interested citizens who work with the Institute to improve palliative care) and other key stakeholders. The Group was a key channel for communication and awareness raising of the campaign, allowing for wider engagement with member networks.

**Results:** Early and ongoing engagement led to a wide range of collaborative activities:

- 12 palliative care personal experience videos, with stories from both people with palliative care needs and professionals
- 1500 members of the public were surveyed to assess public perceptions of palliative care, in both Northern Ireland and the Republic of Ireland, which informed key messaging.
- 8495 new public information leaflets were distributed.
- 18 online events, with 2, 500 delegates attending, a 25% increase on 2020.
- 95 items of media coverage across national, regional and online media outlets.
- 11 million- overall reach of the 2021 campaign (traditional/digital/social media)

**Conclusion:** The impact of the 2021 Palliative Care Week campaign demonstrated early connections and collaboration with partners are key for best results. Partners, and their networks were supported by AIIHPC to promote palliative care including hosting events, participate in media opportunities and highlight their organisations work in the area. Engaging early with people with palliative care needs secured personal stories which are essential to raising awareness of benefits of palliative care for people living with palliative care needs.

**Abstract ID: 254**

**Abstract Type: Free Communication - Loss and grief**

### Equipping people to be Grief Kind

**Bianca Neumann\***<sup>1</sup>

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It can be hard to know what to say or do that might help someone living with grief. Sue Ryder created a national movement of grief-kindness to give people confidence to support grieving people. Aoun et al (2018,2020) found that people most frequently got more effective and helpful support from family and friends, not professionals, but they feel ill-equipped and unprepared.

Bereavement projects reaching more than local communities are very rare.

This national project meets Ambition 6 in the Ambitions for Palliative and End of Life Care 2021-2026 in particular:

‘Each community is prepared to help: I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.’ A public health approach to bereavement needs to be in the public domain, getting to people’s usual living environments, outside of healthcare settings.

The project started with an email journey people could sign up for, covering grief topics and providing practical tips as well as psycho education. This was followed by a series of celebrity podcasts on sharing how others supported them well, and less so, through grief. Sue Ryder designed modern sympathy cards and tips on what to write in them enabling and equipping people to continue conversations with the grieving person. Buses also advertised for this cause. Publications achieved national and regional coverage with a total reach of 30 million people and, to date, 50000 have ordered the free cards. More activities and products are planned to equip more people to be Grief Kind.

**Abstract ID: 256**

**Abstract Type: Poster - ACP & End of Life communication**

### Role of end-of-life care planning in knowledge of partner’s preferences for end-of-life aspects

**Sarah Vilpert\***<sup>1</sup>, **Clément Meier**<sup>1,2</sup>,  
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**Background:** Surrogate medical decision-making at the end of life is common and the patient’s partner is often the person who must make these critical decisions. The challenge of surrogate medical decision-making is to make decisions that best fit the patient’s wishes. End-of-life (EOL) discussions and care planning should contribute to make the healthcare proxy’s decision more compliant with patient’s wishes. This study investigates subjective and objective knowledge of partner’s preferences for the end of life, as well as the contribution of partner’s EOL care planning to this knowledge in a nationally representative sample of older adult (58+) couples living in Switzerland (N=625).

**Methods:** Subjective knowledge is based on self-rated awareness of partner’s EOL preferences. Objective knowledge is assessed by measuring how accurately respondents predict their partner’s preferences for ten EOL care aspects and three medical treatments. The contribution of EOL discussion and care planning to subjective and objective knowledge of partner’s preferences for the end of life is examined using regression models.

**Results:** The vast majority of respondents thought they knew their partner’s wishes for end of life. The proportion of wrong predictions of partner’s preferences for the ten EOL care aspects varied between 7.5% and 46.1%, and for the three medical treatments between 18% and 42.9%. Respondents whose partner discussed their EOL preferences with them, completed an advance directive and designated them as a healthcare proxy were more likely to think they

knew their partner's wishes for the end of life in general and for medical treatments. Furthermore, respondents who reported knowing their partner's preferences for the end of life were more likely to score higher in correct predictions of partner's preferences for EOL care aspects and treatments. Finally, respondents whose partner completed an advance directive and designated them as a healthcare proxy were more likely to score higher on accurate predictions of partner's preferences for EOL treatments.

**Conclusion:** Being a couple is not enough to assess one's partner's EOL preferences correctly. Communication about EOL wishes among the couple and individual EOL care planning should be encouraged, as they improve the level of subjective and objective knowledge of partners' EOL preferences.

**Abstract ID: 257**

**Abstract Type: Symposium**

### Challenges of research about peer support in palliative care

*Erica Witkamp<sup>1,2</sup> (chair), Kate Lorig<sup>3</sup> (chair), Catherine Walshe<sup>4</sup> (speaker), Nancy Luu<sup>\*1</sup> (speaker), Judith Rietjens<sup>1</sup> (speaker)*

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**Background:** Many people in the community deal with a life threatening illness, either themselves or of beloved ones. Support from peers, who have experiential knowledge of and experience with the consequences of living with such a disease, may have unexploited and mutually beneficial potential. Research on peer support in palliative care is in its infancy and challenging due to vulnerability of peers and participants, and non-classic roles and responsibilities. Moreover, traditional research methodologies may not fully comply with the complexity of peer support.

**Objective of the symposium:** To share experiences about the potential and the challenges of conducting research about peer support in palliative care. We will obtain a broad perspective covering individual and group peer support,

face-to-face as well as online, cancer as well as dementia, and research experiences from different countries (US, UK, NL).

**Content:** The symposium will be chaired by Prof. Erica Witkamp (NL) (Care for Family Caregiving) and Prof. Kate Lorig (US) (Patient education, Peer support and Self-management).

- Presentation 1: Prof. Catherine Walshe (UK): will present the methodological challenges of the PACT feasibility randomized controlled trial exploring individual in-person peer mentoring for people with advanced cancer, focusing on equipoise, recruitment and outcome measurement.
- Presentation 2: Ms. Nancy Luu (NL) will discuss the mixed methods SMART-study that evaluates the digital peer led, peer support group program for patients and relatives living with advanced cancer, focusing on self-referral recruitment, collaboration with peer-facilitators, and results of the conversations analyses.
- Presentation 3: Dr. Judith Rietjens (NL) will discuss novel strategies to study peer support, elaborating on recent experiences studying self-management strategies of persons with dementia through a novel combination of citizen science of book clubs, text-mining of dementia ego documents, and design thinking.

**Abstract ID: 258**

**Abstract Type: Poster - Literacy & Education**

### Perceptions and knowledge of end-of-life medical situations among older adults in Switzerland

*Clément Meier<sup>\*1,2</sup>, Sarah Vilpert<sup>1</sup>, Gian Domenico Borasio<sup>5</sup>, Jürgen Maurer<sup>1</sup>, Ralf J. Jox<sup>3,4</sup>*

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**Background:** Perceptions and knowledge regarding end-of-life health and healthcare can influence individuals' advance care planning, such as the completion and content of advance directives. We aim to assess older adults' perceptions of medical

end-of-life situations in Switzerland along with their accuracy and corresponding associations with sociodemographic characteristics.

**Methods:** A nationally representative sample of adults aged 58 years and older who participated in wave 8 (2019/20) of the Swiss part of the Survey of Health, Ageing, and Retirement in Europe. Subjective likelihood of 11 end-of-life situations on a four-point scale (very unlikely (0-25%), rather unlikely (26-50%), rather likely (51-75%), very likely (76-100%)).

**Results:** Older adults' perceptions of end-of-life medical situations in Switzerland were rather heterogeneous and often inaccurate. Study subjects overestimated the success of cardiopulmonary resuscitation, the utility of a fourth cancer chemotherapy, as well as a hospital admission for pneumonia and artificial nutrition and hydration in the context of imminent death but underestimated the general effectiveness of pain management in this situation. Less than 28% of older adults correctly assessed the likelihood of dying in a nursing home, hospital or at home, respectively. Inaccurate views were more frequent in men ( $p < 0.01$ ) and individuals with financial difficulties ( $p < 0.05$ ), while adults aged 75+ ( $p < 0.01$ ) and respondents from the German-speaking part of Switzerland ( $p < 0.01$ ) had more accurate perceptions.

**Conclusions:** The wide variation and low accuracy of end-of-life perceptions suggest considerable scope for communication interventions about the reality of end-of-life health and healthcare in Switzerland.

**Abstract ID: 259**

**Abstract Type: Poster - Community**

**Charters are not enough: supporting volunteering at the volunteer level**

**Steven Vanderstichelen<sup>\*1,2</sup> (chair), Ros Scott<sup>1,3</sup>, Leena Pelttari<sup>1,4</sup>, Catherine Renard<sup>1</sup>, (facilitator)<sup>5</sup>, Catherine Walshe<sup>1,6</sup> (facilitator)**

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Volunteers are a vital part of hospice and palliative care in many countries. They often find themselves

at the interface between health services and communities, between formal and informal care provision, and are uniquely able to traverse these spaces to meaningfully contribute to quality of life and care for people faced with serious illness, death, dying and loss. In 2017, the EAPC Task Force on Volunteering launched the EAPC Madrid Charter to advocate for increased support for volunteering in hospice and palliative care. The Charter was widely shared and signed and was considered valuable for policy negotiation in the support for volunteering in the long term. However, volunteers coordinators found that it lacked value as a practical tool for immediate change at the volunteer organization level in how volunteering is supported and valued. The aim for this workshop is to develop preliminary ideas for tools and resources that volunteers and volunteer coordinators can use to effect change in the support of volunteering in the short term. (E.g., coordination, training, representation in the organization.) These tools are intended to complement the charter's predominant policy-level applicability. The workshop will start with a short presentation on the EAPC Madrid Charter and its evaluation, highlighting the need for tools for immediate action to improve practical and organizational support for volunteering at the organizational level. Participants will then be divided into smaller groups of 6-8 participants. Moderators will take notes. Participants will be invited to share good practices, existing tools and to think about what resources and tools they miss when trying to improve support, training and conditions for volunteers in hospice & palliative care. Moderators will summarize for each group. Proceedings from the workshop will be shared with participants after the conference, plans will be drafted to continue the conversation beyond the conference.

**Abstract ID: 261**

**Abstract Type: Poster - Various Topics**

**Fostering empathy and compassion through art observation**

**Julie Rodeyns<sup>\*1</sup>, Free De Backer<sup>1</sup>**

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Visual Thinking Strategies is a museum activity that invites a group of participants to (under the guidance of a certified facilitator) enter into a discussion with a visual art work. Designed in order to promote the aesthetic development of participants,



scientific research has shown that regular participation in VTS-sessions also promotes, among others, compassionate listening, comfort with ambiguity and tolerance for other views among participants. For these reasons, the method is increasingly used to promote compassion in school or workplace environments and among health care students and professionals (medical students, doctors, nurses, social workers, therapists, . . .).

This hands-on workshop will invite the workshop participants to participate in a 30 min. Visual Thinking Strategies session, that, afterwards, will be discussed and analysed together. We will dissect the method, discuss some of its important pillars (such as the key mechanisms used by the facilitator and the selection of the artwork) and uncover the factors that contribute to fostering empathy and compassion.

**Abstract ID: 262**

**Abstract Type: Workshop**

**Building dementia-inclusive communities through arts and culture: the case of the Academy of Bruges**

*Els Robaey<sup>1</sup>, Annelore Boone<sup>1,2</sup>, Julie Rodeyns<sup>\*3,4</sup>*

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Art and culture can play an important role in improving the life quality of people who are ill and/or ageing and of their informal caregivers. In the framework of the transnational project 'Dementia in Cultural Mediation' (DCUM), partners from Belgium, Denmark, Spain and the Netherlands jointly created a hands-on toolbox, aimed to inspire and empower local and regional communities and art, cultural or health organisations to develop artistic/cultural activities in order to create more dementia-inclusive communities. The project drew on the rich experience of different professionals working in healthcare and cultural institutions such as libraries, art museums or civil society organisations and was continuously reviewed by a European reference group consisting of highly experienced experts in the field of dementia, research and the arts and representatives of the end-user group (people with dementia and their informal caregivers).

This hands-on workshop will introduce the participants to one of the best practices involved in the DCUM project. The Academy of Bruges organises weekly art classes for people with dementia,

embedded in the regular program of the art school. During these classes, all visual media are explored (painting, drawing, printing, ink, charcoal, mixed media, . . .). The organizers will share their methodologies and give useful tips on how to work artistically with persons with dementia. Testimonials from persons with dementia will provide an insight into how they experience and value these art classes.

DCUM was realised with support from the European Commission.

More info: <https://dementiainculturalmediation.eu/>.

**Abstract ID: 263**

**Abstract Type: Free Communication - Death literacy and knowledge of death systems**

**End-of-life health literacy: a validation study of a new instrument, the End-of-life Health Literacy Scale (EOL-HLS)**

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**Background:** Measuring health literacy allows to assess individuals' competencies to deal with health issues; it influences how individuals perceive their health problems, communicate with health care professionals, or make medical decisions. The end of life is commonly characterized by one or several diseases, the use of healthcare services and requires individuals to make complex medical decisions. Although the end of life concerns everyone, the level of competencies of individuals to get through this stage of life has been little explored. This study aims to fill this gap by validating a new instrument, the End-of-life Health Literacy Scale (EOL-HLS), assessing the level of competencies to deal with end-of-life medical situations in a representative sample of older adults aged 58+ living in Switzerland.

**Method:** We use data from the Swiss wave 8 (2019/2020) of the Survey of Health, Ageing

and Retirement in Europe. Based on the seminal work of Nutbeam (2000), end-of-life health literacy skills are measured using a series of questions on the difficulty in understanding medical interventions, finding information, communicating, deciding in advance, and choosing end-of-life care options. In addition, we also compare the distributions in sub-groups of the population from the EOL-HLS and the European Health Literacy Survey questionnaire (HLS-EU-Q16).

**Results:** We used explanatory and confirmatory factor analysis to determine the factor structure of our instrument. Preliminary results confirmed the suitability for performing factor analysis (KMO = 0.924, Bartlett's test of sphericity statistically significant), a three-factor model was established and showed good fit properties (CFI = 0.964, TLI = 0.958, RMSEA = 0.047, SRMR = 0.067). Results also indicated good reliability with a Cronbach alpha's for the instrument of 0.93. The associations found between individuals' sociodemographic characteristics and the HLS-EU-Q16 were also present in our instrument, but the EOL-HLS was more sensitive to others sub-population groups.

**Conclusions:** The EOL-HLS is a reliable and valid instrument to be used in the Swiss population. It may be helpful in testing, e.g. the hypothesis that individuals with a low end-of-life health literacy are at risk of being disadvantaged in their quest for goal-concordant care at the end of life.

**Abstract ID: 265**

**Abstract Type: Workshop**

**Looking forward: a workshop exploring the priorities for public health palliative care research in the coming decade**

*Steven Vanderstichelen (chair)\*<sup>1-4</sup>, Sonja McIlpatrick<sup>4-5</sup> (facilitator), Carol Tishelman (facilitator)<sup>4,6</sup>, Luc Deliens (facilitator)<sup>1-4</sup>, Joachim Cohen (facilitator)<sup>1,2,4</sup>, on behalf of the EAPC Reference Group on Public Health & Palliative Care (Prof. Luc Deliens (BE), prof. Joachim Cohen (BE), dr. Steven Vanderstichelen (BE), prof. Samar Aoun (AUS), Dr. Marie-Charlotte Bouësseau (FR), prof. Allan Kellehear (UK), prof. McIlpatrick (NI), prof. John Rosenberg (AUS), dr. Libby Sallnow (UK), and prof. Agnes van der Heide (NL))*

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Present-day interest in public health perspectives in palliative care research have resulted in the emergence of a diverse range of research approaches. However, there is currently no consensus on a common research agenda for Public Health Palliative Care research. Through this open workshop, the European Association for Palliative Care (EAPC) Reference Group on Public Health and Palliative Care invites experts in public health palliative care from various backgrounds and parts of the world to together explore ideas about the most pressing research priorities for PHPC. The workshop fits within an ongoing Delphi study approved by the EAPC board.

During the workshop, we will briefly present the ongoing Delphi study conducted by the reference group and summarise findings from an earlier open meeting held to identify preliminary priority research themes and topics. Dividing participants into smaller groups of 8-15 people, two sets of group discussions will be held. A first round of discussions will invite participants to reflect critically on the presented findings, focusing on identifying gaps and adding new insights to the previous findings. A second round of discussions will ask each group to focus on a single theme and try to formulate broad, but concrete research questions to be addressed in future studies. Each group will have a facilitator to take notes and to report back to the rest of the participants. Notes will be collected after the workshop, synthesised and shared after the congress. Insights gained during this workshop will ultimately contribute to an EAPC white paper. Expected learning outcomes of this workshop include:

- (1) insights into the most pressing research topics for PHPC in the next decade, according to researchers, practitioners and community developers worldwide;
- (2) a stronger understanding of the current gaps in PHPC research; and
- (3) a first view of what a common research agenda for PHPC research may look like.

**Abstract ID: 267**

**Abstract Type: Poster - COVID**

**The relation between distress and feeling appreciated when providing end-of-life care during the COVID-19 pandemic (CO-LIVE)**

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**Background:** The COVID-19 pandemic impacted end-of-life care and healthcare professionals (HCPs) providing this care. The appreciation of HCPs, as shown by society in the beginning of the pandemic, seemed to decline gradually, which could influence the well-being of HCPs.

**Aim:** To examine distress in HCPs who provided end-of-life care during the COVID-19 pandemic and the association with feeling appreciated and understood.

**Methods:** An online survey in Sept. 2021 among HCPs who provided end-of-life care during the COVID-19 pandemic. The 9-item Well Being Index (WBI) was used to assess distress in HCPs. We dichotomized the WBI score as  $<2$  versus  $\geq 2$ , which is associated with a serious degree of distress and risk of adverse consequences. Items about whether respondents felt appreciated as a HCP and felt understood were also included. Descriptives and logistic regression analysis were used to describe the association between WBI scores of  $\leq 2$  and feeling appreciated and understood, corrected for gender, age, work setting and occupation.

**Results:** 125 HCPs (65% nurses, 15% physicians, 20% other) from different settings (16% community, 13% nursing home, 22% hospital, 24% hospice, 26% other) responded (88% women; mean age 52 years). Of all respondents, 34% had a WBI score of  $\geq 2$ , 14% did not feel appreciated and 42% did not feel understood. Not feeling appreciated and not feeling understood were significantly associated with a WBI score of  $\geq 2$  (OR 4.12 and 9.21, respectively).

**Conclusion:** A substantial proportion of HCPs who provided end-of-life care during the COVID-19 pandemic experienced high levels of distress, which is related to not feeling appreciated and to not feeling understood. Since previous studies found that high WBI scores are related to a higher risk of burnout and intention to leave one's current position, it is important to minimize distress in HCPs. Greater appreciation from employers and society may be helpful in this regard.

**Abstract ID: 270**

**Abstract Type: Free Communication - Equity and Access**

**Reflecting on roles, responsibilities, and choices when providing palliative care in socially disadvantaged areas**

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**Background:** Living in a socially disadvantaged area is often associated with poorer outcomes at the end of life. Understanding the views and attitudes of palliative and end-of-life care professionals working in socially disadvantaged areas could help identify practices that facilitate more equitable care.

**Methods:** Qualitative semi-structured interviews were conducted with 42 healthcare professionals providing generalist and specialist palliative care in three different regions of North West England. Data were analysed using thematic analysis and cross-case analysis techniques.

**Results:** Participants differed in their views on their role and responsibility in responding to unfair social differences at the end of life, which sometimes impacted the type of care provided in socially disadvantaged areas. When confronted with experiences of death and dying that challenged professional palliative care goals, some participants drew on patient choice narratives to try to rationalise differences in dying.

**Conclusion:** The findings reveal a tension between a desire to promote individual agency and a need to recognise the structural causes of inequities at the end of life. Greater reflection on this tension may help palliative care professionals

facilitate more authentic choices, using language that acknowledges the socioeconomic context in which people make decisions at the end of life.

**Abstract ID: 271**

**Abstract Type: Workshop**

**Compassionate communities in Colombia, Argentina, and Switzerland. How to assess their effectiveness? An interactive workshop**

*Valentina González-Jaramillo<sup>\*1</sup> (speaker), Alicia Krikorian<sup>2</sup> (speaker), Vilma Tripodoro<sup>3</sup> (speaker), Magui Jorge<sup>4</sup>, Andri Christen-Ceballos Rosero<sup>1</sup>, Maria Clara Velez<sup>2</sup>, Debora Lema<sup>4</sup>, Tatiana Noguera<sup>2</sup>, Elena D'Urbano<sup>4</sup>, Sofia Zambrano<sup>1,5</sup>, Steffen Eychmüller<sup>1</sup> (chair)*

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**Background:** The compassionate communities' (CC) movement seeks to normalize conversations about death and dying and to empower members of the communities to support each other. Despite their contribution to wellbeing, there are no tools or evaluation models that measure their effectiveness nor their impact on society, or on the well-being of patients, caregivers, and healthcare professionals. Agreement on a common core outcomes set (COS) for evaluating CC programs will allow comparability of different CC initiatives around the world. Additionally, a COS will help community leaders and researchers to recommend politicians and administrators to actively engage in the development of CC and to fund local strategies through proven effective examples from other communities.

**Aims:** This interactive workshop will encourage participants to engage in the definition of a first and preliminary COS for developing compassionate communities. Based on a protocol, which received a seed partnership funding in early 2022, the workshop will start by presenting the CC programs of three particularly different cities: Medellín, Buenos Aires, and Bern. Using mind mapping to capture ideas and visualize and adapt findings, workshop participants will next be guided to reflect on examples from their own contexts and to consider questions such as: Which are commonly agreed goals in my community?, can we define measurable outcomes applicable across these different contexts?,

which could be the process to capture, create and gather potential outcomes that reflect various perspectives from the communities?

Through open discussion, this workshop will be an open and inclusive first step of elaborating an international COS for CC. Following the methodology for COS development, as proposed by the Core Outcome Measures in Effectiveness Trial (COMET) initiative, participants may even agree at the end to build an international COS group for further exchange and collaboration under the umbrella of the PHPCI conference.

**Abstract ID: 272**

**Abstract Type: Poster – COVID**

**Hospice care - where do we go now?**

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**Background:** Dame Cicely Saunders started the modern hospice movement in 1967. A movement of social change to improve the care for the dying and those closest to them. Nearly 60 years on, hospices now face challenges of growing demand, decreasing resources and balancing medical and public health approaches to dying, death and grief. The Covid pandemic has exacerbated these challenges for hospices who have become partners in the healthcare system.

Dr Barbara Gale has over 40 years experience of working in hospice and palliative care with the last 14 years as a hospice CEO. Barbara led the development of an Equip Provide Strive hospice strategy founded on public health and asset based approaches, which was presented at the last conference.

**Presentation:** Barbara will reflect on the challenges of implementing such a strategy during a pandemic - for staff, volunteers, Trustees, potential funders, local stakeholders and for herself as a leader. The presentation will conclude with a range of options and questions about how hospices can lead the way in embracing public health approaches which improve death literacy in the population and ensure the delivery of specialist services for those who require it.

**Outcomes:** Participants will hear a personal reflection from Barbara Gale on the challenges of



leading an organisation through change and will be challenged to consider the beliefs which are helping and hindering the progress of hospice care as an integral part of a part of a public health approach to dying, death and grief.

**Application to PHPCI:** Hospice have been seen as the experts in dying, death and grief for many years. Many hospices are also now embracing Compassionate Communities and Community Development approaches to widen their reach into local communities, where services are hard to reach. However, the presentation reflects on why public health approaches to death and grief are still not always incorporated into local and national policies and strategies.

**Abstract ID: 274**

**Abstract Type: Free Communication - Compassionate cities**

### **A Compassionate City Charter in the USA embracing belonging, loss, and resiliency**

*Diane Witt<sup>\*1,3</sup>, Mary Ann Boe<sup>2,3</sup>, Kristen Abbott-Anderson<sup>1,3</sup>, Kelly Krumwiede<sup>1,3</sup>*

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**Background:** When contemplating the creation of a Compassionate City in the United States one must take into consideration that America has a death-denying culture as well as high levels of loneliness and social isolation. Recognizing the need to move upstream of the end of life to be successful in United states, we intentionally shifted from PHPCI's priority of death, dying, caregiving, and bereavement to a focus on belonging, loss, and resiliency.

**Methods:** Utilizing Community Based Collaborative Action Research methodology, focus groups were held with leaders from fifteen sectors of the community. Only seven of those sectors were able to move forward with sector member focus groups due to the COVID pandemic.

The group facilitator initiated a discussion about what it means to belong and then invited participants to share their stories around loss; what was helpful and what might have been helpful had it been available.

The focus group transcripts were analyzed for patterns, themes, and best practices. These were shared with the sector leaders who were then charged with determining the "best practice" that they would adopt as a policy to support the members of their sector and include in the Kato Towns Compassionate Charter.

**Results:** Through the focus group process, actionable items were created to promote and normalize compassionate conversations around belonging, loss, and resiliency to provide more support and care for one another during life's difficult times including death, dying, caregiving, and bereavement. These best practices initiated the Kato Towns Compassionate Charter.

**Conclusion:** The Kato Towns Compassionate Charter with civic celebration and media has catalyzed our work as a Compassionate Community. All organizations, neighborhoods, and business in Kato Towns are invited to participate. The process is simply a matter of gathering in conversation circles, sharing stories around loss and resiliency, and joining the Charter with their own best practice.

**Abstract ID: 275**

**Abstract Type: Free Communication - Loss and grief**

### **When death is all around: A rapid review of grief and bereavement experiences of social and community service workers**

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**Background:** People experiencing structural vulnerabilities (e.g., poverty, homelessness, racialization, disability) face barriers to accessing health and end-of-life (EOL) care. They often receive informal support from social and community service workers in harm reduction, shelter and housing, and outreach roles. Although these workers fill systemic gaps in serious illness and EOL care they typically feel unsupported in doing so. To understand this growing public health palliative care (PHPC) concern, our rapid review

collected and synthesized literature on work-related experiences of grief and bereavement among these workers.

**Methods:** We systematically searched six electronic databases (APA PsycINFO, CINAHL, MEDLINE, Sociological Abstracts, Social Work Abstracts, Web of Science) to identify literature that captures the intersection of work-related grief and bereavement experiences with the stated occupational and supported population criteria. Citations and full-text articles were screened, and data abstraction was conducted by two independent reviewers in accordance with Cochrane Rapid Reviews Methods Group (2020) guidance.

**Results:** Our rapid review found a dearth of literature on the grief and bereavement experiences of social and community service workers. Instead, distress in this worker group is framed as an issue of individualized mental health such as vicarious trauma, compassion fatigue, or burnout. Without the recognition of the collective impact of social inequities this caregiving work will remain unsupported, unrecognized, and distressing. This review illustrates the need for community-led, informal, grief and bereavement supports.

**Conclusions:** Our results are a first step to understanding how social and community service workers in these environments experience grief and bereavement and to conceptualizing more effective support interventions. Responding to workers' grief and bereavement needs outside of institutional and traditional EOL settings is a growing PHPC concern and a pressing matter of health and care equity.

**Abstract ID:** 278

**Abstract Type:** Free Communication - Death literacy and knowledge of death systems

**"What does the public know about palliative care?": a population-based survey in two urban and two semi-urban cities**

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**Background:** Palliative care has evolved rapidly and a public health approach towards palliative care is of growing interest. Community engagement in palliative care has shown signs of promise. A necessary prerequisite for this is that the public knows what palliative care entails and what it can achieve. The aim of this study was to investigate the public knowledge about palliative care and to identify key predictors of knowledge.

**Methods:** A cross-sectional survey among 4400 citizens in two urban and two semi-urban cities in Flanders, Belgium measured knowledge of palliative care using the Palliative Care Knowledge Scale (PaCKS). Data regarding demographic characteristics, and familiarity and experience with palliative care, serious illness, suffering, death and loss were also collected.

**Results:** Response was obtained for 2008 (45,6%) citizens. The mean score on the PaCKS was 7,93 (SD 3,39; range 0-13). 82,2% of the respondents answered correctly that palliative care is not specifically for people with cancer and 85% knew that palliative care is not only for older adults. Common gaps in knowledge related to palliative care being not only for the last 6 months of life (44% correct), that stress can be addressed by palliative care (35,6% correct), and that palliative care can improve the ability to participate in daily life (32,2% correct). Demographic variables (i.e. age, educational background) and familiarity and experience showed to be significantly positively correlated with the level of knowledge ( $p < 0,05$ ).

**Conclusion:** The findings suggest that gaps and misconceptions around palliative care persist among the general public. Demographic characteristics and exposure to palliative care, death, suffering and loss should be kept in mind in the development and targeting of effective strategies to address these gaps in knowledge. Such strategies will be instrumental in increasing public engagement around issues of serious illness, suffering, death and loss.

**Abstract ID: 280****Abstract Type: Free Communication - Policy and Vision****Strategies for implementation of a palliative approach: a scoping review**

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**Background:** The palliative care discourse today emphasises integration of palliative care in non-specialised palliative care services, across populations and settings, throughout the palliative care continuum. Therefore, there is a need to identify and build upon published research in the palliative knowledge translation field, to learn from and enhance further development. The aim of this study was to map strategies for knowledge translation of a palliative approach to care into non-specialized palliative care services for adult patients.

**Methods:** A scoping review was performed, searching six databases for original research published between 2010 and 2019. The search strategy was developed to identify the Population: adult patients in need of health care, the Concept: knowledge translation strategies of a palliative approach, and the Contexts: non-specialised palliative care services. Language was restricted to English. Following the screening process, data was extracted and categorized according to research characteristics, palliative care continuum focus, sources of evidence, and knowledge translation strategy.

**Results:** 183 articles met the inclusion criteria. Among the studies, most common areas of focus were cancer contexts, hospitals, countries with high human development index (HDI), while early palliative care was only represented in a minority of articles. The majority included health-care professionals as participants. A variety of

knowledge translation strategies were used, of which none proved to be outstanding. Essential components of the research designs were to a large extent unspecified.

**Conclusion:** This review confirms that previous suggestions to apply knowledge from implementation science to enhance palliative care in the non-specialised palliative care field have been practiced to some extent. Further use of knowledge translation theories can enhance the field. To strengthen a public health perspective, studies should focus on other contexts than hospitals (e.g. primary care), and move further up the palliative care continuum towards early palliative care. Furthermore, research outside countries with high HDI is of great significance. Careful reporting of research design, contexts, and mechanisms at work can enhance this field.

**Abstract ID: 281****Abstract Type: Free Communication - Various Topics****"Humanae: human transformation towards caregiving". A project to promote compassionate care education in a school of health science**

*Alicia Krikorian<sup>\*1</sup>, Claudia Villegas<sup>1</sup>, Maria Camila Guzmán<sup>2</sup>, Hellen Castañeda<sup>1</sup>, Carlos Sampedro<sup>3</sup>*

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**Background:** Historically, education regarding aspects such as empathy, communication, therapeutic relationships, teamwork and self-care, has been part of a hidden curriculum in medicine and nursing programs. In recent years, due to a crisis in the human dimension of healthcare and increased burnout in healthcare staff, there has been global tendency to develop integrated and cross-curricular educational agendas in health-care programs related to the humanizing and compassionate dimensions of care.

**Aims:** To describe curricular contents, educational practices, attitudes and knowledge of teachers and students regarding compassionate care at a school of health sciences in Colombia.

**Methods:** a descriptive, observational and mixed quantitative-qualitative study is being conducted. First, a description and analysis of the curricular contents of the medicine and nursing programs is currently being done. Then, a survey to identify educational practices and contents regarding compassionate care education (including themes such as compassion, caregiving, empathy, communication, therapeutic relationship, teamwork, selfcare) in medicine and nursing will be administered. Teachers ( $n = 524$ ), current students (group leaders and student-monitors  $n = 96$ ), and formal students (enrolled in postgraduate programs at the school of health sciences  $n = 64$ ) of both programs will be invited to complete the survey. Finally, focus groups including teachers and current and formal students of the programs will be conducted for an in-depth exploration of educational contents and practices, attitudes, and knowledge towards compassionate care at the school of health sciences. Data will be analyzed using a mixed-methods approach.

**Impact:** This study will help identify specific issues and facts related to compassionate care education at the school of health sciences, which will constitute a baseline towards the development of a cross-curricular, integrated, and visible education strategy in compassionate care. As a result of this effort, a second phase of the Humanae project will be conducted to optimize educational strategies towards compassionate care using a collaborative work approach including, teachers, current and formal students and directives.

**Abstract ID: 283**

**Abstract Type: Free Communication – Various Topics**

### **Dying in the Margins: Creating Co-Produced Images with People Experiencing Financial Hardship at the End of Life**

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**Background:** Photography has been used as a medium for exploring the lived experiences of marginalised groups in social research for decades, however, visual research methods are rarely used in the context of end-of-life research.

Contemporary images representing end of life experiences lack diversity and are generally not taken by the person who is themselves dying. The UK based Dying in the Margins project aimed to use participatory visual methods to enable people at the end of life who were also experiencing poverty and deprivation to produce images which they felt represented something of their experiences of living out their dying at home whilst struggling to make ends meet.

**Methods:** The Dying in the Margins project was guided by participatory and appreciative methodologies. The following visual methods were specifically chosen because they have a track record of fostering participation among disenfranchised groups: photo-voice; digital storytelling; and professional photography strongly guided by participatory practice.

**Results/ conclusion:** We present a selection of images from the project which we subjected to a robust visual analysis. On the one hand, images can be seen as simply being illustrative of social problems. Our images could be used to illustrate some of the financial hardships our participants were navigating e.g. high heating and electricity bills, high transport costs, accessibility issues. On the other hand, images can be seen to have a more evocative, interpretative function in telling a multi-faceted and complex story of someone's life in the context of that life coming to an end. In this project, we were focused on creating evocative visual narratives which supported people's agency, portraying their struggles and their idiosyncrasies to engender respect, empathy and discussion.

**Abstract ID: 284**

**Abstract Type: Free Communication – Compassionate cities**

### **Compassionate network: social transformation towards caregiving". Report of a compassionate community in Medellín, Colombia**

**Alicia Krikorian<sup>\*1</sup>, Maria Clara Vélez<sup>1</sup>, Francy López<sup>2</sup>, Juan Felipe Cañaverall<sup>3</sup>, Hellen Castañeda<sup>2</sup>, Diana Restrepo<sup>2</sup>, Luz Estella Torres<sup>1</sup>, Juan Camilo Arboleda<sup>3</sup>, Tatiana Giraldo<sup>3</sup>**

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**Background:** Compassionate communities (CC) have developed all over the world and today they constitute a public health strategy in palliative care. However, each CC differs in its strategies, target population, goals and achievements. Describing experiences, activities, approaches and accomplishments is useful to share insights, further develop other CC's and establish compassionate networks.

**Aims:** To describe activities and achievements of a compassionate community program in Medellín, Colombia.

**Methods:** The Compassionate network of Medellín, Colombia has been continuously working to promote compassionate care in the general audience and, particularly towards highly dependent people and their caregivers. The program has 4 lines of work: 1. Promoting of a compassionate care culture in society; 2. Training in compassionate care for caregivers; 3. Contributing to the development of caregivers' networks; and 4. Articulating efforts of individuals and organizations in Medellín towards caregiving and caregivers. An interdisciplinary team of professors and students at a university work together to conduct the activities and further develop this compassionate network.

**Results:** 74 organizations in Medellín and surrounding territories are part of the compassionate network, including hospital and healthcare facilities, nursing homes, patient associations, non-governmental organizations, governmental organizations, universities. Monthly meetings to articulate efforts and develop caregiving tools are conducted. Informal alliances between governmental and non-governmental organizations have promoted the development of caregiver networks in different neighbors. Permanent educational and sensitization activities and courses are conducted, including aspects such as compassion, compassionate care, caregiving abilities, self-care strategies, development of caregiving networks, etc. Specific achievements in each line of work and beneficiaries of the activities conducted in each line will be presented. Particularly, a description of experiences during the Covid-19 pandemic will be presented.

**Conclusions:** The compassionate network in Medellín, Colombia has had a permanent and positive impact on caregiving practices in the city, particularly in challenging times for the society.

**Abstract ID:** 285

**Abstract Type:** Poster - Equity and Access

**Equity, diversity and inclusion in palliative and end of life care practice and research: personal reflections**

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A public health approach to palliative care aims to centre on communities and views community as equal partners in health promotion at the end of life. There is increasing recognition by policy makers in countries such as the UK of the benefit of this approach to address health and social inequalities. This has resulted in services being keen to 'engage with' communities and a greater focus on equity-based palliative care research.

During this presentation, the author will reflect on her experience as a woman who comes from a materially deprived and racially minoritised background who works within palliative care clinical practice and research in the UK. Using an intersectional lens, she aims to describe her personal experience of belonging to a so called 'disadvantaged community' in need of 'engagement' and trying to work towards better diversity, inclusion and equity in palliative care practice and research.

She will reflect on why before the pandemic she did not feel she belonged in palliative care or academia due to the lack of diversity and inclusion, systemic bias and imposter syndrome. She will discuss the profound impact of COVID-19 and George Floyd's death on compelling her to understand more about public health and health inequalities—something poorly addressed or role-modelled during medical school and post-graduate training.

She will talk about why she chose to stay in academia, despite not belonging—why inequity is more than a subject of interest. But also why, two years on, she has felt physically, mentally and emotionally exhausted working in this space, how this manifest and why this occurs to those from minoritised communities advocating for equity.

She will also explore the positives of working with true allies (and what this looks and feels like), the benefits of bringing a disparate community of minoritised individuals together and the liberation

and vulnerability that comes with bringing your whole self to your work when you have worked hard to get people to look past your past.

The author will explore what diversity, inclusion and equity mean in reality for community members, especially those with multiple intersecting marginalised identities.

**Abstract ID: 286**

**Abstract Type: Workshop**

**Compassionate Communities Sustainability Guide – Strengthening the initiative's planning phases to achieve sustainable community-led impact**

*Bonnie Tompkins\*<sup>1</sup>, Aliya Mamdeen<sup>1</sup>, Jonathan Faulkner<sup>1</sup>, Leorah Granholm<sup>1</sup>, Laura Ndoria<sup>1</sup>*

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Pallium Canada believes Palliative Care is everyone's business, including the community. To engage the community, Pallium is mobilizing the Compassionate Community movement by creating resources that support those leading the work. The newest resource – Compassionate Community Sustainability Guide, builds on the Compassionate Communities Startup Toolkit's impact. The Compassionate Community (CC) movement has seen substantial growth in Canada since 2015; however, there is a documented struggle to move beyond the startup stage. Social change research highlights the need for initiatives to incorporate sustainable practices, which increase the likelihood of progressing to the scale and spread stage and achieving sustainable impact in their community.

This session will cover the guide, a collection of established best practices and tools for community-led development, which acts as an easy-to-use road map. The key topic areas covered in the guide include leadership, program planning, funding, language, trust, community engagement, and partnerships.

During this workshop, participants will learn the following:

- Stages of development for social change movements like CCs

- Best practices used in sustainable community-led initiatives and the tools to engage with these best practices
- The essential best practices to incorporate right away and tools to support the work
- How to efficiently use the guide for years to come

The ideal participant for this workshop understands the CC movement and has already had community conversations. During the workshop, participants will engage with key tools to support incorporating the essential best practices.

Participants can take this knowledge and the guide back to their community and engage with the content in a manner that makes sense for their initiative. The Compassionate Community Sustainability Guide is designed to continue catalyzing the engagement of communities and cities in public health palliative care.

Pallium Canada would like to acknowledge that Health Canada funded the Compassionate Communities Sustainability Guide. The presenter of this workshop is an employee of Pallium Canada and co-authored this resource.

**Abstract ID: 287**

**Abstract Type: Poster – Equity and Access**

**Barriers and challenges to provide palliative care in developing countries - Case of Albania**

*Rudina Rama\*<sup>1,2</sup>, Marinela Sota<sup>2</sup>, Fatmir Prifti<sup>1</sup>, Ali Xhixha<sup>1</sup>, Anila Selmani<sup>1</sup>, Liliana Sorra<sup>1</sup>*

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**Background:** Palliative Care (PC) service cannot meet the high demand in country level. The diversification of the services is very limited, outpatient oriented and don't reflect the holistic approach to address different needs of patients. In country there is no pain control unit in the public hospitals and PC is not yet a distinct specialty or sub-specialty in the medical field and is not integrated into the public health care system. The study aims to explore the barriers and challenges for the provision of palliative care in the health care system in Albania.

**Methodology:** To achieve the objectives of the study there were used the qualitative data collection method, through desk review documents and 24 interviews with key informants.

**Results:** Albania has made distinctive efforts to produce legislation, regulations and strategies for PC; there is an identified need to revise the standards and protocols of PC; doctors and nurses have different knowledge and understanding of PC service, drug use and availability; the system doesn't respond to the needs of patients due to the lack of services and resources; the patients with other diagnosis than cancer do not receive PC and are excluded de facto of the system.

**Conclusions:** There is a gap between PC policy, normative documents and the implementation level; there are geographically differences of law implementation and drug availability, accessibility and affordability; the number of patients in need of PC in Albania is increasing and the projected number of patients/year will put the system in crises or will seriously endanger the access of patients for services.

**Abstract ID: 288**

**Abstract Type: Poster - Euthanasia & MAID**

**Creating narratives to support experiences of medical assistance in dying in Canada: qualitative investigation of nurses' views**

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**Background:** It's been 6 years since Canada passed a federal legislation that allows eligible adults to request medical assistance in dying (MAID). With good reason, much attention in Canada has been focused on public views and physicians' experiences of MAID. Nurses' experiences reported by international studies, particularly from Belgium where euthanasia has been legal for 20 years, demonstrate the relevance of taking an interest in the narratives of nurses to better understand how to improve the process of MAID. The aim of this poster is to create a space for nurses to participate in this discussion by creating a narrative from their stories collected during a doctoral thesis.

**Methods:** A qualitative meta-synthesis was conducted (n = 11 articles) to provide a review of the experience of Canadian nurses since the legalization of MAID. In-depth interviews were conducted with 9 nurses working in MAID context. A thematic analysis was used to analyze the data and an existential analysis was used as an interpretative framework.

**Results:** This poster present a narrative scheme created from themes gathered from both meta-synthesis and interviews with participants. We present various questions related to both gaps and facilitating elements identified in MAID's context, among which: how does the vision of nursing influence the experience of MAID? What is a "good death" in this context? What makes the interprofessional teams generally more comfortable and what does not? How does professional communication and support spaces help through MAID process?

**Conclusion:** The difficulties reported in the context of MAID being found in the sphere of value conflicts in clinical situations, it is important to ask how to help nurses and other caregivers to accompany patients at the end of life. Making room for experience, particularly in dedicated communication spaces could in this sense promote better understanding and interprofessional cohesion in this particular palliative care setting.

**Abstract ID: 289**

**Abstract Type: Free Communication - Loss and grief**

**Quality Palliative Care: Interventions for Grieving and Bereaved Informal Caregivers in Canada**

*Carly Thrower*\*<sup>1</sup>, *Carol Barrie*<sup>2,3</sup>, *Sharon Baxter*<sup>3,4</sup>, *Meryl Bloom*<sup>5</sup>, *Maria Carolina Borja*<sup>6</sup>, *Anica Butters*<sup>6</sup>, *Deborah Dudgeon*<sup>3,7,8</sup>, *Ayeshah Haque*<sup>1</sup>, *Suzanna Lee*<sup>6</sup>, *Iqra Mahmood*<sup>6</sup>, *Mehrnoush Mirhosseini*<sup>3,9</sup>, *Raza Mirza*<sup>1,10</sup>, *Kate Murzin*<sup>3,11</sup>, *Ankita Ankita*<sup>1</sup>, *Neerjah Skantharajah*<sup>1</sup>, *Christina Vadeboncoeur*<sup>3,12,13</sup>, *Andrew Wan*<sup>1</sup>, *Christopher Klinger*<sup>1,3,10,14</sup>

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**Background:** Within palliative care, informal caregivers play a crucial role as part of the interdisciplinary care team. Ensuring high quality care includes providing effective grief and bereavement supports. There is a paucity of research offering insight into these interventions. The objective of this scoping review was to examine the types of grief and bereavement interventions geared toward informal caregivers from a Canadian perspective.

**Methods:** A scoping review of the literature was conducted following Arksey and O'Malley's 5-step framework. Seven electronic healthcare and social sciences databases (e.g., CINAHL, PsycINFO, MEDLINE, etc.) were searched, along with the websites of several Canadian organizations to identify grey literature sources. Relevant articles were screened for inclusion criteria and a thematic content analysis was employed to summarize key findings.

**Results:** 33,006 initial records were generated and 18 sources marked for inclusion. The themes that emerged from these articles were: (1) classification of the intervention (e.g., creative, educational, psychosocial, and comparative analyses), (2) the format of the intervention (e.g., delivery channels, setting, frequency, and timing), and (3) the intervention target (e.g., caregivers, healthcare professionals, and volunteers). Each of these factors were considered in the design and evaluation of bereavement services for informal caregivers in Canada.

**Discussion/Conclusions:** There is a need for further evidence and more robust studies to evaluate the effectiveness of interventions for supporting informal caregivers through grief and bereavement in Canada. Interdisciplinary collaboration between healthcare providers, policy makers, researchers, and caregivers is necessary to further develop, evaluate, and scale interventions.

**Abstract ID: 290**

**Abstract Type: Free Communication - Arts and end of life**

**Illuminating artists' engagement with individuals with palliative care needs: a convergent mixed methods study**

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**Background:** Internationally, artists engage individuals with palliative care needs in a wide range of settings, however little is written regarding artists' practices. The aim of this convergent mixed methods study was to address a gap in the literature regarding artists', health professionals' and program coordinators' experiences and perceptions in an effort to shed light on artists' work in palliative care.

**Methods:** Within a convergent mixed methods design, an integrative review of the literature was conducted to inform the study from design to dissemination. An online, cross-sectional survey with professionals with experience of artists engaging individuals with palliative care needs provided breadth in description of the range, scope, benefits, and risks of practice. Semi-structured, in-depth interviews with artists, health professionals, and program coordinators garnered a depth of understanding. By engaging professionals across disciplines, multiple points of view were triangulated to enrich understanding of a complex and understudied phenomenon.

**Results:** Systematic literature review (N = 7), online survey (N = 101) and interviews (N = 32) identified consistencies and variations in international artists' professional practices in palliative care. Across all three data sets, wide variation in artists' education, training, and practices existed primarily across a continuum of contexts from hospital to community settings. Artists benefited from literacies in their art form/s; palliative care, grief, and developmentally- and culturally-informed approaches to adapting arts engagement. A set of 'vital signs' were generated from side-by-side comparison of findings, which offered indicators of thriving, resilient engagement of the



arts in palliative care at the levels of participants, artists, families, arts teams, healthcare teams, and institutions. Recommendations for future research included probing awareness of artists' work in palliative care within communities and across the interdisciplinary fields of arts in health and palliative care from medicine to public health.

**Conclusions:** This study highlights the value of articulating an international range and scope of artists' work in palliative and end-of-life care spaces in order to advance practice. Critical analysis of patterns of consistency and variation in artists' work in palliative care advances efforts to recognize, value, and provide infrastructure in support of meaningful and effective arts engagement for artists and participants alike. To the researchers' knowledge, this study is the first effort to reach internationally across palliative and end-of-life care settings, health conditions, and art forms in an effort to document a range and present a continuum of artists' engagement in palliative care.

**Abstract ID: 293**

**Abstract Type: Poster - Community**

### **Implementation of community-based palliative care in Primary Health Care in integration with Specialized Outpatient Care**

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**Background:** Palliative care (PC) assistance in Brazil is heterogeneous and centralized at the hospital level. Health Care Planning (PAS) is a methodology for organizing the macro-processes of Primary Health Care (PHC) and Specialized Ambulatory Care (AAE), changing its practice in order to qualify a given care network, based on the reference theory of the social construction of PHC, which includes PC as one of the macro-processes to be developed.

**Methods:** Through 10 thematic steps, PAS is implemented nationwide by the PlanificaSUS project in 18 Brazilian federative units. Step 8 directly involves CP. The execution of the operational model involves management workshops (planning/monitoring) and the mentoring process

in the territory with: Workshop (general concepts); Tutorial Workshops (technical operational moments in the services, where tutors and staff plan, execute and monitor actions related to the processes worked on); Tutoring alignments for tutor preparation; Monitoring meetings during the dispersion period, as additional support for the implementation of new processes.

**Results:** Step 8 includes Workshop themes: Demystifying PCs; The CP macroprocess; Who can benefit from CP. Topics of tutorial workshops divided into three sub-steps: Person-centered palliative approach; Communication; At what point in the course of the disease is the person?; How the user can participate in care decisions; Care in loss and grief; How to support the person and the family when death approaches? Short distance learning courses for healthcare teams: Symptom management; Palliative care in PHC. Management monitoring workshop that evaluates the training process and palliative care indicators.

**Conclusion:** Step 8 of PlanificaSUS brings perspectives of changes in the scope of public health in terms of access to and provision of PC in Brazil.

**Abstract ID: 294**

**Abstract Type: Free Communication - Compassionate communities research**

### **Canadian Evaluation Toolkit – Supporting those leading Compassionate Communities Initiatives with their evaluation**

*Bonnie Tompkins\*<sup>1</sup>, Dr. Eman Hassan<sup>2,3</sup>, Julie Darnay<sup>4</sup>, Deborah Sattler<sup>4</sup>, Emilie Lessard<sup>5</sup>, Pam Martin<sup>2</sup>*

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The creation of the Canadian Compassionate Communities (Com Com) Evaluation Toolkit started in August 2018 through a collaboration between Pallium Canada, BC Centre for Palliative Care and Hospice Palliative Care Ontario. The three organizations teamed up to co-lead and co-sponsor the development and testing of the toolkit in consultation with local Com Com initiatives throughout Canada. In 2020, the Canada Research Chair in Partnership with Patients and Communities joined the project team in an advisory role.

The objective of the Evaluation Toolkit is to increase the capacity of Com Com champions in Canada to

evaluate their own initiatives and share their experiences, results and learnings with their peers. To ensure the appropriateness and acceptability of the toolkit by the intended users, including community members who lack experience and knowledge of evaluation, the project team recognized the need for a toolkit that makes the creation of an evaluation plan simple, easy, engaging and at no cost.

During the toolkit development, the project team held several community consultations to gather end-user feedback and ensure the toolkit resources meet their needs and expectations. Once the feedback was integrated, the evaluation framework and toolkit were refined and then piloted in three communities.

A user-friendly, interactive website has been developed to ensure the evaluation framework and toolkit are accessible to the community. The website provides basic information about evaluation and a compilation of free evaluation resources. A key feature of the website is that it allows the users to create an evaluation plan customized to their initiative through an interactive and automated step-by-step process.

This session will provide an overview of the project phases and the milestones achieved to date, including the Canadian Com Com definition, common stages of Com Com development in Canada, evaluation framework, and online toolkit. The target audience for this session includes those leading Com Com initiatives at the ground level, any organization supporting initiatives, policymakers and evaluators.

### Competing Interests

The Canadian Compassionate Communities Evaluation Toolkit was funded internally by the project team partners. The Authors acknowledge a conflict of interest as they work for the organizations on the project team.

**Abstract ID: 295**

**Abstract Type: Workshop**

### Let's find a warmer lexicon for loss

**Pieter Deknudt\***<sup>1</sup>

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Around the globe, many peoples have created beautiful mourning cultures which are influenced

by their local beliefs, traditions and visions concerning death and loss.

The bases of these mourning cultures are strongly connected with their language. Parallel to the 50-words-for-snow-theory, which states that the indigenous Inuit people have an abundant lexicon for various types of snow, due to their regular contact with it, it is surprising that quite some Western languages do not boast a great deal of vocabularic elements which make up the lexicon concerning death.

Without too lengthy theoretical discussion, this workshop aims to spark creativity in a common search for a more modern, useful, practical or poetical lexicon around this subject.

The idea is to make this 'quest' for words together, while building mindmaps, tasting the connotations of words, and to hopefully come up with our own 50-words-for-death glossary to accurately describe emotions related to loss.

Time to tap into our inner linguistic and poetry skills!

**Abstract ID: 296**

**Abstract Type: Free Communication - Health Promoting Palliative Care**

### Palliative Rehabilitation, an urgent need in the field of Public Health

**Gabriela Rezende\***<sup>1</sup>, **Cristiane Aparecida Gomes-Ferraz**<sup>2</sup>, **Ingrid Giovanna Ferreira Imbroinisi Bacon**<sup>3</sup>, **Marysia Mara Rodrigues do Prado De Carlo**<sup>4</sup>

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**Background:** Palliative Rehabilitation assists people with life-limiting illnesses to maintain their active participation in everyday life, adapt to losses resulting from the illness process, maintaining a sense of dignity, competence and resilience.

**Objective:** To present the conceptions of nurses and occupational therapists from England and Brazil about palliative rehabilitation in oncological care.

**Methods:** Multicentre study, with qualitative approach and cross-sectional design, carried out with 18 nurses and 18 occupational therapists. The research was approved by the Research Ethics Committees of the University of São Paulo, Brazil and Kingston University, England. Data collection was carried out from May 2020 to July 2021, through interviews by video-conference. Data was analysed according to the method of reflective thematic analysis.

**Results and discussion:** Three units of meaning were analysed: 1 – Structure of palliative care services (Brazilian and English health systems); 2 – Concepts about rehabilitation for palliative care cancer patients; 3 – Assistance provided by nurses and occupational therapists in Brazil and England to the palliative care cancer patients. Although the propositions are different between the two countries, there is a tendency towards integration between rehabilitation and palliative care, finding its most complete expression in palliative rehabilitation. Palliative rehabilitation brings a holistic and person-centred conception, based on the integrality and multidimensionality of care that, in addition to physical symptoms, includes care with psychological stress, socio-family difficulties and spiritual suffering. Its objective is to improve the quality of life even at the end of life.

**Conclusion:** Palliative rehabilitation is increasingly being included in the care provided to people with life-limiting illnesses, which is a humanitarian, public health and human rights need. However, it is still neglected in the distribution of resources and provision of services, especially in countries like Brazil. There is a need for public palliative care policies that address palliative rehabilitation around the world.

**Abstract ID:** 297

**Abstract Type:** Poster - Cancer

### **Total Pain in The Context of Palliative Care and its Assessment in People with Advanced Lung Cancer**

*Cristiane Aparecida Gomes-Ferraz<sup>\*1</sup>,  
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**Introduction:** Understanding the concept of Total Pain in a multidimensional way, as proposed by Cicely Saunders, and evaluating the painful experience of patients with a life-limiting disease, means considering the relationship between biopsychosocial and spiritual factors.

**Objective:** To analyze the complexity of the multidimensional assessment of Total Pain in patients with advanced lung cancer, with emphasis on social factors.

**Method:** Exploratory, cross-sectional study carried out with 81 participants, of both sexes, diagnosed with advanced stage lung cancer. Data were collected using Brief Pain Inventory, Palliative Outcome Scale and a socioeconomic data questionnaire, which assessed the multidimensionality of patients' pain and symptoms. **RESULTS:** Among the results of the analysis, those related to the participants' social factors stand out here. The analysis showed that female participants, aged between 51 and 75 years, smokers, with low education and with financial difficulties, reported more pain and total suffering. The association showed that, for female participants, a relative increase of 49.22% (CI 95%, 1,1834 - 1,8817) in mean pain score is expected compared to male participants. Regarding education, a relative increase of 74.53% (CI 95%, 1,0529 - 2,8929) is expected in the average level of pain among participants with primary education. The results also showed that patients with low income showed an increase in symptoms such as pain, anxiety and sadness, presenting a relative increase of 9.99% (CI 95%, 1,0470 - 1,1554) in the average score, in relation to participants with a higher level of education.

**Conclusion:** The results indicate that social difficulties related to the context in which they live, financial and family issues and level of education were associated with worse results in the physical,

emotional, social and spiritual dimensions of patients with advanced stage lung cancer. It demonstrates, therefore, that it is necessary to pay attention to the integrality of each person, apply a holistic approach to their care at each stage of the Palliative Care process, which must include social aspects and carry out a multidimensional assessment of Total Pain to improve the care provided and the quality of life of these patients in palliative care.

**Abstract ID: 298**

**Abstract Type: Poster – COVID**

### **Impacts of the COVID-19 pandemic on palliative care: a qualitative and multicentre study**

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**Background:** The increase in the number of cases of COVID-19 had an intense impact on services and health care professionals. It has been causing important imbalance between the supply and demand for intensive care beds and exposed limitations of supplies and availability of trained health professionals to deal with the pandemic.

**Objective:** To present how nurses and occupational therapists understand the impacts of the COVID-19 pandemic in the context of palliative care, in England and Brazil.

**Methods:** Multicenter study, with qualitative approach and cross-sectional design, carried out with 18 nurses and 18 occupational therapists. The research was approved by the Research Ethics Committees of the University of São Paulo, Brazil and Kingston University, England. Data collection was carried out from May 2020 to

July 2021, through interviews by videoconference. Data was analysed according to the method of reflective thematic analysis.

**Results and discussion:** Three units of meaning were analysed: 1 – The rapid response to the COVID-19 pandemic; 2 – The suffering resulting from the pandemic; 3 – The process of death and solitary mourning; 4 – Positive aspects arising from the crisis. People affected by COVID-19 can experience a lonely death, putting their family members at high risk for complicated grief. The importance of implementing PC during pandemics and moments of crisis is highlighted. Alternative methods of providing PC can also be used, such as telemedicine, tele counseling and bereavement support groups. Despite the multiple demands and difficulties, changes in services provided professional growth and favored access to Primary Care.

**Conclusion:** The restrictions imposed by preventive measures and social isolation reflecting on the daily life and health of the world population. This process highlighted the need for integrated PC models in the face of the COVID-19 pandemic. Health systems must consider the need to increase the capacity to provide PCs to this population, to allow people to be treated in a dignified and adequate manner in all settings and especially in end-of-life care.

**Abstract ID: 299**

**Abstract Type: Free Communication – Compassionate cities**

### **Healthy End of Life Project (HELP) Ottawa: From Engaging, Gathering and Mapping to Collectively Evaluating, Learning and Translating**

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**Background:** Inspired by the community development framework arising from the 'Healthy End



of Life Project (HELP); offering and providing, asking and accepting help' in Australia, Compassionate Ottawa, a citizen-led movement in Ottawa, Canada, collaboratively designed HELP Ottawa.

**Methods:** Designed as a community-based, participatory action research initiative, which draws on a mixed-methods, case study design, HELP Ottawa is based in two urban community health centers (CHCs) and two suburban faith communities (FCs) in Ottawa. Launched in the fall of 2019, and operating within multiple, consecutive waves of COVID-19, three active-oriented cycles have unfolded 1) Engaging, Gathering and Mapping; 2) Planning-Implementing- Evaluating-Sustaining (PIES); and 3) Collectively Evaluating, Learning, and Translating.

**Results:** Conversations with stakeholders across all sites ( $n = 89$ ) supported general learning about the history and context of each site while also illuminating specific supports for people who are frail (e.g. structural vulnerabilities), people living with advanced illness, people who are dying, people who are caregiving, and people who are grieving. Subsequent baseline data about experiences, comfort, and confidence in providing and receiving care were collected with CHC community members including staff, volunteers, clients/family and community partners ( $n = 105$ ), and FC community members including clergy/staff, lay leaders, parishioners, and community partners ( $n = 78$ ). Each site collaboratively planned, implemented and evaluated a range of community-led programs, resources, pathways and events ( $>40$  initiatives) to normalize conversations, increase community capacity and capability around illness, dying, caregiving and loss, and strengthen linkages across people, neighbourhoods, communities, social (care) services and health services and systems. Visual and arts-based methods were integrated to build public knowledge around illness, dying, caregiving, and grieving

**Conclusion:** Moving forward, the project team is engaging more centrally with collective impact approaches, supporting our understanding of what needed to happen, how well it worked (and for whom), and what difference these initiatives have made to develop a collaborative end of life culture.

**Abstract ID: 302**

**Abstract Type: Free Communication - Community engagement and development**

### **Allies or Interlopers? End of Life Doulas and Palliative Care**

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**Objectives:** This presentation will review findings from the first international study of end of life doulas. The primary focus will centre on the ways in which early innovators and key stakeholders within the movement compare and contrast the end of life doula role to existing care roles within hospice palliative care.

**Methods:** In-depth semi-structured interviews with 21 early innovators and key stakeholders in the end of life doula movement in Australia, Canada, the United Kingdom, and the United States. Interview questions focused on the emergence and current practices of end of life doulas, and the benefits and challenges of integrating this care role within existing health care systems. Participants were identified through historical reputation and public presence, professional and community connections, and selective snowball sampling. Our analytic strategy was abductive and iterative, employing a social constructionist approach.

**Results:** Analysis resulted in three themes that described the relationship between end of life doulas and hospice palliative care: faithful, differentiated, and as extension. "Faithful" articulated a perspective that end of life doulas adhere to the originary holistic philosophy of hospice palliative care, often contrasted to the challenges faced by health care professionals operating within conventional health care systems. "Differentiated" articulated a distancing and difference from hospice palliative care, particularly nursing and volunteer roles. "Integrated" articulated a belief that end of life doulas can provide a crucial professional role within existing hospice palliative care teams. Participants commonly employed more than one perspective, and often acknowledged tension between perspectives.

**Conclusions:** Results indicate that the end of life doula movement, as it grows, may be experiencing ambivalences of philosophy and practice similar to the historical development of the hospice palliative care movement within conventional medical systems and services.

**Abstract ID: 305**

**Abstract Type: Free Communication - Loss and grief**

### **Bereavement Companionship Programme**

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**Background of the Bereavement Companionship Programme (BCP):** Death is a constant of human life, and every person experience bereavement in their lifetime. Societies and cultures have various mechanisms for helping individuals cope with bereavement. This includes assistance in completing final rites and rituals, and organising social support measures.

Bereavement is a period of intense grief, involving a range of complex emotions. However, communities are often deprived of proper knowledge and skills for addressing the grief and loss associated with death. Moreover, over the years, the circumstances and features of bereavement have changed. Increasing feelings of isolation and lesser avenues to communicate have compounded grief. The Covid-19 pandemic has made the situation more complicated.

**The Program:** BCP is conceptualised and collaboratively implemented by 3 global organisations; Mission Better Tomorrow, Institute of Palliative Medicine WHOCC and Death Literacy Institute. It is operated as a 15 hour programme titled; 'Foundation Course in Bereavement Support', to help communities build capacities to support its bereaved members. The goal of the programme is not to create trained professionals, but to prepare community members to be companions to a bereaved friend, colleague or family member. The topics include; Knowing Oneself, Understanding Concepts of Bereavement, Grief and Loss, Compassionate Communication, Group Discussions Based on Culturally Appropriate Case Studies and Assignments.

**So Far:** BCP was introduced in Kerala, India with around 1000 people registering for the

course. Applicants are divided into batches of 30 and sessions are organized over 3 days. 120 participants successfully completed the course so far. BCP proved its replicability within 3 months of its initiation. Recently, the 1st international batch consisting of participants from Bangladesh completed the course. The feedback from participants from both local and international batches were highly encouraging.

**Conclusion:** BCP is rapidly evolving. Within a short period of time, BCP has garnered high appreciation from participants and interest from various palliative care organizations around the globe. BCP is now being scaled up rapidly through continuous training and networking.

Note: We have included the abstracts in the overview, for which the presenting authors have confirmed their attendance at the conference.

**Abstract ID: 307**

**Abstract Type: Free Communication: Culture, philosophy and spirituality**

### **Supporting the dying process through volunteer biography services**

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**Background:** The prospect of imminent death precipitates the asking of existential questions which can lead to suffering in the terminally ill individual if meaning cannot be found in their experience. Biographical interventions are an important tool to construct meaning, however, such interventions are not widely implemented by healthcare professionals, in part due to the resources required. Volunteer biography services involve regular meetings between terminally ill individuals and trained, community-based volunteers to document a life history, which is made available to the individual and the family.

**Methods:** This study involves a mixed-methods evaluation of the impact of the volunteer-run Sacred Heart Community Palliative Care Biography Service in Sydney Australia. Participants are recruited from each stakeholder group: the terminally ill individuals, their family

members, the volunteers, the volunteer trainers and supporters, and the referrers. Effects of the intervention on the spiritual wellbeing of patients and their families will be investigated, as well as the way the service supports communities to improve societal understanding of and support for the dying process.

**Results:** Biographical interventions have been shown to increase the quality of life and alleviate depression. Engagement with volunteers facilitates social connection and interactions, which relieve

isolation and loneliness, and the telling of one's own life story allows individuals to frame their legacy in their own terms. This has been shown to benefit both the patient and the grieving family.

**Conclusion:** Biography services into community palliative care represent one way in which individuals and their families can process, make sense of and celebrate the closure of a person's life outside of the medical context. Use of volunteer biographers makes introduction of biography services in palliative care feasible.