8th Public Health Palliative Care International Conference: Building Bridges between Science and People

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Welcome from the PHPCI President

Dear Colleagues

Dear Friends

It brings me immense joy to extend a warm welcome to every one of you to the 8th Public Health Palliative Care International Conference in Bern, the cozy and beautiful capital city of Switzerland. We invite you to experience the charms of Bern, an ancient city at the gateway to the breath-taking high mountains of the Alps.

Two years ago, we met in Bruges, Belgium, for the 7th PHPCI conference and experienced there a fantastic conference embedded in the Compassionate City of Bruges. Next to the conference program, we had the exciting artistic track and during the conference week, the Compassionate City was organizing the city festival, embracing several local initiatives on the themes of serious illness, long-term care, mourning and loss. I am very pleased that we can offer you this year an equally interesting and exciting conference in Bern.

During the conference week, several activities and events will be hold in the City of Bern, in collaboration with the Compassionate City Bern. The scientific and cultural programs have been carefully prepared by the committees and this gathering promises to showcase the many aspects of public health palliative care from all over the world. The cultural engagement with the City of Bern provides an opportunity to see how the civic, social and healthcare worlds can partner to support compassionate communities and compassionate cities.

This conference promises to be an extraordinary gathering, showcasing the pinnacle of progress in public health palliative care, a practice and research domain that is rapidly evolving. Addressing the complex needs of the seriously ill, death, dying, loss and bereavement requires collaboration across professional groups and disciplines. Let us embark together on a journey to identify and engage researchers and practice experts in public health palliative care, fostering creativity and innovation.

We encourage each of you to take full advantage of this unique opportunity at the conference to connect with fellow attendees both within and beyond the confines of our conference venue. It is my fervent hope that the conversations, insights, and knowledge gained during this conference will galvanize public health palliative care worldwide, charting a course toward a brighter future for all those in need of compassionate care.

I extend my profound gratitude to the members of the preparatory committees (Organizing Committee, Scientific Committee, Committee of the City Programme, Committee of the German-Speaking

Countries, Committee of the Swiss Programme) and to all volunteers for curating an exceptional program, rich in content and relevance. All names of people involved in these committees can be found on the conference website (https://www.phpci2024.org).

Lastly, I extend my deepest appreciation to each one of you for your commitment to public health palliative care. Your presence at the 8th PHPCI Conference in Bern is a testament to your dedication, and I eagerly anticipate the opportunity to engage with you in stimulating discussions and meaningful interactions at the conference. On behalf of the Council of PHPCI, I wish you all a stimulating and engaging conference.

Luc Deliens, president of PHPCI

Welcome from the joint chairs of the international Scientific Committee

On behalf of the scientific committee of the 8th World Congress of Public Health Palliative Care International, PHPCI 2024 in Bern we warmly welcome you from across the world to this beautiful and historic city. We wish to acknowledge and thank the outstanding contributions from delegates across the world, and to our highly motivated scientific committee representing all continents. We are pleased to present this stimulating conference abstract book to you.

More than ever, the topics of dying, caregiving, and grieving represent pressing and urgent challenges across all societies: an end of life in dignity is far from guaranteed and the necessary confidence, capacity, and resource are dramatically lacking across the world. This is why research, practice, and support must raise its voice and become political – drawing on evidence, and united in a will for change. As highlighted in recent landmark papers, we realize the enormous challenges for the near future: the increasing number of people in need for support until death, the worldwide injustice in access to high quality health care, the need to recognise and respond to the wider determinants of living and dying well, the decreasing number of professionals entering or staying in their job, and the lack of a political will to develop skills and confidence for caring for each other in solidarity.

But hope is in the air: this abstract book showcases many initiatives and projects that demonstrate that the creativity and conviction in how we connect with each other at the end of life reflects the level of mutual respect across the whole life course. We are convinced that this conference will mark the beginning of many new ideas not only on paper, but in reality. Through ‘Building Bridges’, the conference’s theme, we hope that everyone will be moved to shift the current status quo through the connection with others. Building bridges within and across the communities we are part of. Even if small in size compared to the dimensions of the global challenges before us, the sheer number and potential of the presented projects offer a unique opportunity to stay optimistic: compassion is the essence for our global survival.

Come to Bern and feel this spirit!

Steffen Eychmüller **Libby Sallnow**

Joint chairs of the Scientific Committee

8th Public Health Palliative Care International Conference

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ID: 108
Abstract Type: Poster

Topics: Policy and advocacy, Care in humanitarian contexts

Keywords: palliative care, displaced community

The missing cancer and palliative care in displaced community in Northeast of India

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Background: Cancer is a chronic illness needing long treatment. This includes late toxicity management in case of cure and palliative care if cure is a distant possibility. Northeast part of India shares international border with Bangladesh and both sides had witnessed geopolitical uncertainty since India's independence in 1947. Unrest and military rule in East Pakistan made the citizens to flee to India which continued even after the creation of the new country Bangladesh in 1971. However, the poor migrants are not eligible under the public health scheme due to lack of proof of citizenship.

Objective: The study objective is to bring out the cause and issue of missing cancer care in displaced community and find possible mitigation strategies.

Design: This is a prospective analytical study evaluating health schemes and law of the land.

Methods: We have analyzed the public health scheme and issues of migrants in Northeast India after observing discontinuity in care. Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB PM-JAY) is a national public health insurance scheme of the Government of India that aims to provide free access to health insurance coverage for low-income earners in the country. The scheme is applicable to Indian citizens. In 2019 Government of India passed the Citizenship Amendment Act (CAA) to provide Indian citizenship to the illegal migrants who entered India on or before 31st December 2014. However, the exercise to identify migrants as per the Act is a tedious process and not yet over.

Results: Until the exercise of granting citizenship under the Citizenship Amendment Act is done, the poor migrants who have no proof of citizenship cannot take benefit under AB PM-JAY scheme. Unfortunately, some internally displaced Indian citizens are lacking proof of citizenship and many of them are suffering from chronic illnesses and cancer, however neither afford to pay for treatment nor eligible to get free treatment under AB PM-JAY scheme.

Conclusions: Northeast India migrant issue is a special situation where poor migrants from other country and some displaced poor Indians are not eligible to get cancer care under public health insurance scheme. The Citizenship Amendment Act provides a solution by granting citizenship. However, the tedious process is taking long time and no solution being offered in the interim period.

ID: 109
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Networks and compassionate communities

Keywords: Community, Death, Dying, Health Promotion, Public Health

Improving access to palliative care services in Uganda through health promoting palliative care approach: a case of mobile hospice mbararah

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Introduction: *T*he need for palliative care continues to grow worldwide, due to an increase in ageing populations and a rise in non-communicable diseases. This study was about Improving Access to Palliative Care Services in Uganda through Health Promoting Palliative Care Approach: A Case of Mobile Hospice Mbarara.

Objectives: It was intended to; determine the level of awareness about Health Promoting Palliative Care approach among palliative care providers, examine the extent to which Health Promoting Palliative Care practices were carried out and establish the strategies being utilized by Mobile Hospice Mbarara to improve access to palliative care services.

Methods*:* The study relied on a cross sectional study design where both qualitative and quantitative data collection methods were utilized. The study population comprised of staff and volunteers at Mobile Hospice Mbarara including the. Data was collected using questionnaire and interview guide.

Results: Of the 58 respondents to the study questionnaire and interviews, 47 (81%) were female and 33 (57%) were volunteers while 25 (42%) were current or former staff of Mobile Hospice Mbarara. Majority of the respondents 48 (82.8%) were aware about Health Promoting Palliative Care approach. Only 23 (40%) affirmed that they were aware about the approach that utilizes research and innovation to inform clinical practice and policy. Only 22 (38%) were engaged in discussions about palliative care at community level. The majority 53 (91%) affirmed that political leaders were engaged in organization activities. Empowering staff at MHM was being done through availing staff with refresher courses.

Conclusion: There was still limited access to palliative care services. The study recommended appropriate training to increase staff awareness about health promoting palliative care. The study also recommended more investment around research to obtain evidence to inform and improve clinical practice and policy.

ID: 110
Abstract Type: Poster

Topics: Relationships and connection, Educational approaches

Keywords: education, interdisciplinary, spirituality

Partners in healing: fostering interdisciplinary dialogues about the role of spiritual care in healthcare

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Background: Holistic care requires medical teams who can address the human spirit. Medical training overlooks physicians' care for their own human spirit, making it challenging to be present to patients' spiritual distress or make appropriate chaplaincy referrals. Chaplains often work on the margins, not emboldened to share humanist or spiritual insights in such a medicalized world, even when such insights are crucial to the care plan. The result is that many patients in need of spiritual care never receive it, and many key insights are not shared between these disciplines, to the detriment of patient care.

Methods: Authors designed a 12-hour curriculum in 4 sessions between physicians & chaplains:(1) spirituality and the chaplain-doctor partnership;(2) the chaplain's role on the interdisciplinary team;(3) spiritual & emotional issues related to pain and suffering;(4) death and dying. Aims were: (1) provide spiritual care training to physicians; (2) equip chaplains to step into role as integral members of the team; (3) strengthen the partnership between chaplains and doctors; (4) provide clinicians with space for reflection, creative expression, connection to self and meaning.

Sessions consisted of a case study, large group didactic, small group discussion, creative expression, and cross-discipline partnered reflections.

Authors conducted post-session interviews. A thematic analysis was conducted.

Results: Physicians reported increases in: awareness of chaplain's role; frequency of collaboration with chaplaincy; understanding the importance of a patient's spirit in their care plan; skill in conducting spiritual screenings / histories; ability to traverse difficult existential terrain with patients; awareness of how spiritual distress manifests; recognizing importance of caring for their own spirit in their work; connection to self and work. Chaplains reported an increase in: understanding value of role and voice to the care plan and IDT; confidence engaging the IDT; partnership with physicians in clinical work; understanding of physicians' stressors and distress factors and where chaplains could be helpful.

Conclusions: This curriculum enhanced attitudes and competence of participants in navigating spiritual distress & understanding chaplains and physicians as partners in healing. It suggests that cross-discipline, reflective learning allows for integration of the human spirit in medicine, strengthening comprehensive patient-centered care and mitigating clinician burnout.

ID: 111
Abstract Type: Poster

Topics: Research methods, Artistic and creative approaches

Keywords: life-limiting conditions, paediatrics, environment

Play needs of children living with palliative care needs: a Q methodology study

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Background: Play is every child's right and important in goal setting for their well-being.

Living with palliative care needs challenges the children's play and leads to play disruption.

Objectives: This study investigated the surrounded environmental factors related to play of children with palliative care needs at inpatient healthcare facilities.

Design: A mixed-methods approach was adopted in this study using Q methodology.

Methods: Q methodology data were collected from children living with palliative care needs (n=27) between the ages of 5 and 11 and from their caregivers (n=39) in two countries, Kuwait and the United Kingdom.

Results: The findings indicated that children preferred being with others to play; though, due to their conditions' precautions, this was very limited often. Children had relatively little concern for outdoor, videogames and the type of play to engage in. However, arts and crafts play activities were an exception of as they were important. The findings of the study did not indicate significant cultural differences in the collected data.

Conclusion: This research enables understanding some of the children's play needs that is important to be considered in play goal setting to be incorporated within the inpatient healthcare environments to support children's participation in play. Suggestions are made to create opportunities for social play and opportunities that match children's play preferences.

ID: 112
Abstract Type: Poster

Topics: Relationships and connection, Social and structural determinants of death dying and grieving

Keywords: Family, End of Life, Gender, Experience

Death, Dying and our End-of-Life Wishes: Exploring the Role of Gender and Family Dynamics

Lexi Bryony Sears
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The aim of my research was to offer an authentic personal narrative of what matters to people at the end of their lives. I sought to attend to death as an integral life experience that brings about distinct and meaningful connotations of selfhood and identity. Principally, I sought to understand how (or if) the social construction of gender, and social difference more broadly, is important to our end-of-life experiences and wishes.

To attend to the nuances of experience in death and dying, I adopted an ethnographic people-centered approach with a series of semi-structured interviews which held a loose structure of questions but prioritised storytelling and participant-led interview direction.

One of the most pivotal findings of my study were that death had a catalytic effect on gender identities. My research found that gender had a cognitive role in experiencing and talking about death whereby the differential social roles of women and men proliferate at end of life. This substantiated the analytical standpoint for the study's findings; summarised as:

1. People pre-empt their end-of-life considerations through their understanding of their gender. Notably, my female participants all fixated on the notion of the 'altruistic caregiver' as explanatory of their end-of-life wishes whilst the men were deeply engaged in the finances and 'overseeing' of the family as their priority.
2. Gender foregrounded the justification of people's thoughts and experiences of death through the primacy of their identification of women and men. My participants expressed worries about their death as bounded by their understanding of their own gendered expectations of duty of care for others in their family; largely their children or spouses.
3. Death can reaffirm or challenge gender and its' animations; but this is not linear. Gender knowledges and identities can be equally complicated by our reflections on death, which was exemplified by the men who I interviewed that each experienced a sense of renegotiation in their gender identity through their personal experiences of death. In turn, this changed the way they both felt and experienced emotion.

My research demonstrates the crucial need for future research on death, dying, and gender whilst indicating the pivotal differential priorities which matter to people at the end of their lives. Further, my findings offer a complicated perspective on the differential support needed for men and women in end-of-life conversations.

ID: 114

Abstract Type: Poster

Topics: Technology and digital innovations, Educational approaches

Keywords: Basic Palliative Care Training, Blended Learning, Universal Health Care

Effectiveness of Palliative and Hospice Care Basic Training Manual on non-health and health practitioners' level of knowledge in the Philippines: A preliminary study

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Background: Palliative and hospice care in the Philippines has received increased attention recently, notably with the introduction of Republic Act 11223 or the Universal Health Care (UHC) Law in 2019. This law hopes to maintain the holistic approach in the continuum of care for patients from prevention to treatment, rehabilitation, hospice, and palliation. In preparation for UHC's full implementation, healthcare workers must have the necessary skills, knowledge, and attitude to provide high-quality palliative and hospice care and integrate into local health systems to promote a multidisciplinary and interdisciplinary care approach.

This research study was supported by the Department of Health, Philippines.

Objectives: This study aims to assess the effectiveness of the Basic Palliative and Hospice Care Training Manual in improving the participant's knowledge.

Design: The Basic Palliative and Hospice Training Manual was developed from May to November 2020 through training needs assessment, technical write-shops, and stakeholder consultations. This research study utilized quasi-experimental, pretest-posttest research design.

Methods: Due to the pandemic, blended learning design was utilized on its implementation last 23-27 November 2020, with 36 contact hours. The training was attended by participants from both health and non-health sectors (N=106). A 50-item questionnaire was given pre- and post-training. Pretest scores and Posttest scores were analyzed using Paired T-test to assess the effectiveness of the training.

Results: Only 80 out of 106 (75.47%) participants completed the pretest and posttest with $t(79)= -13.771$, $p < 0.0005$. In comparing the means of participants' test results and direction of t-value, it can therefore conclude that there was a statistically significant improvement in participants' test results following the conduct of basic palliative care training program, from 34.06 + 5.56 correct items to 43.03 + 5.03 correct items ($p < 0.0005$); an improvement of 8.96 + 5.82.

Conclusion: The Basic Palliative and Hospice Training Manual effectively increases and improves the participant's knowledge of palliative and hospice care. Continuous course appraisal and evaluation are still needed to ensure its congruence with the current standards and evidence-based practice. With the results, conducting training in both public and private institutions is imperative.

ID: 115

Abstract Type: Poster

Topics: Relationships and connection

Keywords: Caregiver Burden, Anxiety, Depression, Quality of Life, Mixed-Method Study

Caregiver burden, Anxiety, and Depression on the level of quality of life among primary caregivers of cancer patients in selected institutions in Metro Manila: An Explanatory Sequential Mixed Method Study

Edmar San Jose Elcarte[1,2,3,4,5]

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Introduction: Cancer has been a prevalent cause of death in the world and is considered the second leading cause of deathworldwide, just second to cardiovascular disease (Sudhakar, 2010). In the Philippines, malignant neoplasms, or cancer with approximately 60,000 cases or 10 % from the total of 582, 183 cases of deaths (Philippine Statistics Authority, 2018). Cancer is also considered a national health priority due to its significant implications to individuals, families, communities, and health systems.

Objectives: This study aims to explain the relationship of caregiver burden, anxiety, and depression on the level of quality of life among primary caregivers by their lived experiences.

Design: This research study will utilize an explanatory sequential mixed methods design.

Methods: This is composed of two phases involving quantitative data followed by a subsequent qualitative phase to expand and connect the findings of the quantitative phase. In quantitative phase, the primary caregiver's burden, anxiety, depression, and level of quality of life will be collected through a survey form. While for Qualitative Phase, their lived experiences will also be collected through a semi-structured interview.

In analyzing the data, Statistical Analysis will be employed using Pearson R vs. Spearman rank correlation coefficient which is still subject for assumptions testing for the quantitative phase. Whereas, thematic analysis will be used to analyze the narrations of the primary caregivers' lived experiences.

Finally, integration technique of connecting and developing joint analysis will also be employed prior to the second phase of data collection. This integration technique will be used from the quantitative phase to inform and link to subsequent data collection for the qualitative phase. Mixed-method meta-inferences will also be drawn to show if the results from the quantitative phase are confirmed, discordant, or expanded from the themes created from the qualitative phase.

ID: 116

Abstract Type: Oral presentation

Topics: Relationships and connection, Networks and compassionate communities

Keywords: family care, community involvement, new public health, end of life, social networks

Willingness to support neighbours practically or emotionally: A cross-sectional survey among the general public

Bert Quintiens

Vrije Universiteit Brussel, Belgium

Wider social networks are increasingly recognised in supporting people with care needs. Health promoting initiatives around the end of life aim to foster these social connections but currently provide little insight into how willing people are to help neighbours facing support needs. This study describes how willing people are to help neighbours who need support practically or emotionally, whether there is a difference in willingness depending on the type of support needed, and what determines this willingness. We applied a cross-sectional survey design and distributed 4,400 questionnaires to a random sample of people aged >15 across four municipalities in Flanders, Belgium. These surveys included attitudinal and experiential questions related to serious illness, caregiving and dying. Respondents rated their willingness (scale 1-5) to provide support to different neighbours in hypothetical scenarios: (1) an older person in need of assistance and (2) a caregiver of a dying partner. A total of 2,008 questionnaires were returned (45.6%). Average willingness to support neighbours was 3.41 (case 1) and 3.85 (case 2). Helping with groceries scored highest; cooking and keeping company lowest. Factors associated with higher willingness included optimistic outlook about receiving support from others, family caregiving experience, and prior volunteering around serious illness or dying. People are generally willing to support their neighbours who need help practically or emotionally, especially when they have prior experience around illness, death or dying. This suggests a potentially large informal support network which is available to all. Initiatives promoting social connection and cohesion around serious illness, caregiving and dying may harness this potential through experiential learning.

ID: 117

Abstract Type: Workshop

Topics: Educational approaches, Artistic and creative approaches

Keywords: gamification, storytelling, communication, escape room, education

How to use storytelling and gamification to communicate complex realities? The case of the Stay Room™ and palliative care

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Background: Palliative care is misunderstood by society. It is associated with death and end of life, and people feel fear or anxiety when it is mentioned. This lack of understanding can be an obstacle for access, as people cannot ask for what they do not know or fear. To improve the perception of palliative care, we proposed an innovative alternative: to convey this message through storytelling and gamification. We have designed an escape-room circuit that helps us bring closer a complex reality such as palliative care to an audience with little or no experience on the subject. We have called this dynamic the Stay Room™.

Target audience: researchers, healthcare professionals and other professionals interested in implementing an innovative approach to communicate a complex message such as palliative care.

Learning objective: to understand how to use storytelling as a tool to communicate palliative care to society, based on the Stay Room™ learning experience.

Structure:

-Introduction and presentation of the Stay Room™ (5 minutes): What is a Stay Room™ and how did it begin

-Exercise 1 - Using storytelling (25 minutes): participants are invited to work in groups and come up with the storyline of their circuit. The important parts of storytelling as a tool to transmit complex realities will be explained.

-What we want to achieve: we must define key concepts

-Character and its depth: how to create characters to connect with your audience

-Context of the story: how to communicate through details

-Gamification: how to organize the story in rooms

-Exercise 2 - Production of a Stay Room™ (20 minutes): brief explanation of the things necessary to make the Stay Room™ (what is in our toolbox). Group reflection about the supplies they need to carry out their circuit. We work with them to think of alternatives and solutions to possible obstacles due to lack of resources.

-Conclusion (10 minutes): our evaluation and results. Photos and videos of Stay Room™ from past years (until the end so as not to limit their creativity). Impressions of the participants of previous Stay Rooms™.

ID: 119
Abstract Type: Oral presentation

Topics: Relationships and connection, Educational approaches

Keywords: school-based bereavement program, adolescent coping strategies, palliative education in schools, muliplier seminars for educators, youth engagement in end-of-life topics

"Endlich. Umgang mit Sterben, Tod und Trauer" – a project to teach coping with dying, death and bereavement in secondary schools

Annika Fritzsche
Uniklinik Köln, Germany

Idea: In collaboration with a locally based secondary school in 2007, the idea for a project day for senior pupils on dealing with dying, death and bereavement was born. The objective was to establish a secure space beyond academic demands, encouraging open communication and the development of coping strategies for adolescents.

This initiative supports young people in engaging thoughts on "dying, death and bereavement" while offering guidance without overwhelming them. It empowers adolescents to address emotional needs, fostering openness on this challenging topic and promoting self-help through intuitive competencies, self-worth and personal coping strategies.

Implementation: Initiated in 2009 after discussions with a pilot high school, the project evolved through a two-year pilot program from 2010 to 2012, involving project-based teaching in various schools. This process resulted in a project consisting of three teaching modules (Dying and Death, Bereavement, Suicide), which can be taught in a block over two days or individually as modules, using self-awareness exercises and role plays as teaching methods amongst others. A thorough evaluation encompassing approximately 260 pupils in 12 classes was conducted before and after each session.

In 2012, an expert symposium led to the creation of a handbook for teachers and hospice workers. The second symposium in 2013 shaped a curriculum for training teachers and hospice workers as multipliers. Since 2015, nationwide seminars have trained nearly 500 multipliers, implementing the project in different school forms, supporting pupils in addressing "Dying, Death, and Bereavement."

Lessons Learned: The "Coping with Dying, Death and Bereavement" school project, proven successful, expands nation wide in Germany through multiplier seminars. Regular discussions in an online forum and quality assurance seminars integrate experiences and evaluation results into implementation and teaching materials. Evaluation indicates positive impacts: it strengthens social bonding in class and promotes personal development of both pupils and educators, fostering awareness of palliative medicine and hospice work, and providing preventive approaches to bereavement.

Funding: The project has been funded by Deutscher Hospiz- und Palliativverband (DHPV), Bundesministerium für Familie, Senioren, Frauen und Jugend (BMFSFJ).

ID: 120
Abstract Type: Poster

Topics: Educational approaches

Keywords: Desire to die, wish to hasten death, training, relatives, volunteers

Dealing with desire to die - a topic also for relatives and hospice volunteers

Kerstin Kremeike, Kathleen Boström, Raymond Voltz
Uniklinik Köln

Background: A desire to die is common in seriously ill people, but health professionals often express uncertainty in dealing with it appropriately. Therefore, a multi-professional two-day training program was developed and evaluated to teach self-confidence, knowledge, skills and an attitude in dealing with desire to die. Seriously ill people also express their desires to die to hospice volunteers and (caring) relatives. Due to their closeness to those affected, these two groups may be particularly challenged in dealing with desires to die.

Objectives: To identify the special needs of relatives and hospice volunteers in dealing with desires to die and to develop suitable training and information services.

Design: Qualitative needs assessment.

Method: Focus groups and individual interviews with hospice volunteers and relatives (representatives); based on the insights gained, development, and piloting of target group-specific face-to-face and online formats.

Results: A focus group was conducted with hospice volunteers (N=6) and another with relatives' representatives (N=4), as well as supplementary individual interviews (N=2) with relatives' representatives.

The first focus group revealed a special role for hospice volunteers. They are neither part of the family system nor of the full-time care, they contribute a lot of time and have no therapeutic mandate. Hospice volunteers wish for training courses that focus on their special position, to use language that was understandable to laypeople and preferred face-to-face to online formats.

For relatives, it emerged that, on the one hand, it is important to reflect who really has a desire to die and specifically for whom. In addition, relatives experience particular burdens that result in their own need for support. They wish for short online information and exchange formats in which desire to die could be discussed as neutrally as possible.

Based on these results, the existing training program was adapted for hospice volunteers and a digital two-hour format for relatives was developed, piloted, and evaluated.

Conclusion: During implementation, there was a great demand for different (and differently long) formats, especially among hospice volunteers. Relatives initially appeared to be more difficult to reach, but the mediation by self-help groups revealed a great need for information and exchange on the topic.

ID: 121
Abstract Type: Oral presentation

Topics: Relationships and connection, Networks and compassionate communities

Keywords: Community Volunteers, Signposting PC Needs, Palliative Care Training for Volunteers

Pilot-testing and evaluation of the 'Attentive Visitors' training program to support community volunteers in their palliative care signposting role'

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Background: The 'Attentive Visitors' training program was developed to increase community volunteers' (CV) knowledge, skills and confidence regarding their role, signposting function, and communication to address palliative care (PC) needs with community residents (CR) and healthcare professionals (HCP).

Aims: The aim of the study is to pilot-test and evaluate the training's effectiveness and acceptability for volunteers and feasibility for stakeholders.

Methods: A mixed-method design was used, using a quantitative pre-test/post-test survey at three timepoints to evaluate effectiveness; semistructured interviews to evaluate acceptability and; administrative data analysis combined with a stakeholder group discussion to evaluate feasibility.

Results: Among 59 CV's across 6 locations, 37 completed both modules (training + follow-up moment), 19 participated in interviews and 8 stakeholders took part in the feasibility group discussion. The training had a positive and sustained (at T2) effect on PC knowledge (0.58 less incorrect answers at T2; p=0.011) and self-efficacy in discussing noticed signals of needs with a CR (+0,51 at T2; p<0,001) and HCP (+0,42 at T2; p=0,022). In the qualitative interviews, CV's reported increased awareness of the importance of volunteers, self-efficacy in boundary setting, self-confidence in communicating with CR's, informal carers and HCP's, and emphasized the importance of sharing experiences. CV's reported that the training met expectations and was useful to their volunteering. CV's found the benefits to be in proportion with required efforts. Implementation costs were ranged between €242,41 and €1.238,21 per training, which stakeholders considered feasible for implementation.

Conclusions: The training program was evaluated positively seen it enables CV's to respond better to PC needs and to fully utilize their complementaryrole. This training program can be scaled up and/or integrated into educational programs of stakeholder organizations.

Funding: Kom op tegen Kanker

ID: 122

Abstract Type: Poster

Topics: Relationships and connection, Social and structural determinants of death dying and grieving

Keywords: Pediatric advance care planning, adolescent, leukemia, terminal illness, grief

Advance care planning and palliative care for an adolescent with acute myeloid leukemia

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Background: Pediatric hematologic malignancies are potentially life-limiting and advance care planning is an important aspect in their care. In the Philippines, palliative care is not widely popular, and palliative care providers often encounter pediatric palliative patients and their families who have difficulty in accepting their prognosis.

Objectives: This case study aims to discuss the advance care planning approaches and challenges in an adolescent patient with advanced AML. It describes the palliative careservices provided for a terminally-ill pediatric patient and his family.

Case Summary: This was a case report of a 17-year-old male with AML who had an unsatisfactory response to induction chemotherapy. He was given oral palliative chemotherapy (etoposide) and was referred to the Supportive, Hospice, and Palliative Medicine (SHPM). He had performance status of ECOG 1 on initial referral and was admitted multiple times under Hematology-Oncology (HO) service due to infection complications. He had periodic SHPM follow-ups in his last five months, wherein advance care planning was discussed. Coping and information needs regarding the illness and its poor response to prescribed chemotherapy, as well as the parents' fear to cause depression and hopelessness to the patient posed challenges in the advance care planning. He was eventually able to verbalize DNR-DNI preference but it was not yet finalized into a written advance care document. He was admitted for the last time due to intracranial hemorrhage and received aggressive measures at the emergency room before his parents finally accepted the poor prognosis and requested to discontinue the life-prolonging interventions.

Conclusion: The case showed advance care planning as a dynamic process that could continue even in the terminal phase. It highlighted that consistent follow-up discussions and good documentation were important in the process of ACP. It demonstrated how bedside counseling, continuous information-sharing, and unconditional positive regard might help a family who was initially undecided or opted for aggressive measures to eventually arrive at decisions regarding end-of-life care preferences. Palliative care service should be available and prepared to respect, support, and help facilitate adequate terminal care for the patient and their family. Parents of pediatric patients were at higher risk for pathologic grief. The value of grief counseling for the bereaved family was also emphasized.

ID: 124

Abstract Type: Oral presentation

Topics: Policy and advocacy

Keywords: family caregivers, employment, policy, financial support

Transferable policy solutions for supporting employed end of life family caregivers: Canadian Compassionate Care Benefit

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Background: Family caregivers provide the majority of care for people with palliative and end of life care needs. Due to changing demographics internationally, increasing number of caregivers are taking on a caring role whilst in paid employment, and will continue to work whilst providing care. Policy and employment legislation are key for supporting employed family caregivers, but few countries offer comprehensive support. The Canadian Compassionate Care Benefit (CCB) is one example of a benefit which supports employed family carers, but the potential transferability of the (CCB) to other countries has not been explored.

Aim: The aim of this study was to explore the implementation and impact of the Canadian Compassionate Care Benefit and assess its potential transferability to comparable countries.

Methods: A multi-method design was used, incorporating an integrative literature review and qualitative semi-structured interviews with stakeholders from across Canada. The literature review searched four databases for evidence on the CCB, relevant data were extracted and key themes were identified. Qualitative interviews were undertaken with professional stakeholders with expertise on the CCB, data were analysed using reflexive thematic analysis. In line with multi-method research the findings from the two phases were analysed separately and were integrated at the stage of interpretation.

Results: Data from the integrative review and interviews generated the following key themes: (1) socio-political context leading to the implementation of the CCB; (2) evolution of the CCB policy scope; (3) cost and cost effectiveness of the CCB; (4) positive impacts of the CCB on patient/carer/labour market; (5) perceived problems with the CCB; (6) transferability of CCB to other comparable countries.

Conclusion: The Canadian Compassionate Benefit is one of very few policies globally that provide financial assistance for employed end of life family caregivers. As such the CCB may provide a useful model for future policy developments in comparable countries, including the UK. Whilst the CCB was developed and implemented specifically for the Canadian context, there is significant potential for it to be adapted for use elsewhere. Further research on the Compassionate Care Benefit, particularly around cost-effectiveness, would support international policy transfer.

ID: 125

Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: cooperation, citizen involvement, health in end of life

The "solidarity at end-of-life" project: A concrete example of a compassionate community

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Context and Issues: Inspired by Kellehear's proposals, a Compassionate Community project continues in a north American city of 4.3 million inhabitants. This project is inspired by Healthy Cities, a health promotion approach adopted by WHO, which focuses on cooperation to address the social determinants of health. It is structured around 2 pillars: raising awareness among the general population about the end of life, bereavement, and significant losses, as well as implementing concrete actions for people affected by these problems.

Methodology: Citizens wanting to get involved with isolated people at the end of life were recruited from community forums. The match was made between them, and the palliative patients followed at home by public services. The engaged citizens visited their accompanied person at home on a weekly basis and attended a weekly meeting to share each other's experiences.

Results and discussion: Started in January 2023, these accompaniments are still ongoing. These are based on 3 foundations: traditional accompaniment done through listening and encouragement; networking, where citizens assess who in the end-of-life person's entourage can get involved in helping them; defense (advocacy) and promotion of human rights, particularly regarding public health services and other societal organizations.

Conclusion: At the time of preparation of this proposal, more than 150 different activities had been carried out around the 3 foundations of the intervention. This experience questions traditional volunteer involvement in palliative care and advocates for the engagement of citizens from all backgrounds and walks of life, rather than a professionalization of end-of-life interventions. This type of action could demonstrate that a community-based response to end-of-life issues is not only possible, but essential.

ID: 126
Abstract Type: Poster

Topics: Death and grief literacy, Educational approaches

Keywords: caregiving, dementia grief, psychoeducation, mental health professionals

Development of a psychoeducation tool about dementia grief for German mental health providers

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Background: Dementia grief can be defined as caregivers' emotional responses to the losses associated with dementia. Experiencing dementia grief is associated with different mental and physical health problems. Little is known about mental health providers' knowledge about dementia grief.

Objectives: In this study, a psychoeducation sheet was co-designed with dementia experts, informal caregivers, and healthcare professionals to raise awareness for the concept dementia grief.

Design: The psychoeducation sheet was presented to German mental health providers in an online survey. The 381 participants were psychological or medical psychotherapists, and medical doctors in the field of psychiatry, psychosomatics, psychotherapy, and neurology. Information about participating mental health professionals' demographics included their age, gender, profession, special expertise, work setting, years of experience, having a relative with dementia, caring for a relative with dementia, experience treating people of the age of 65 or older, experience treating caregivers of PwD, continued education on grief and loss, subjective competence in assessing and treating grief.

Methods: The psychoeducation sheet's acceptability, appropriateness, and feasibility were rated. Furthermore, the providers' need for the psychoeducation tool, as well as their opportunity, capability, and motivation to use it was assessed.

Results: Most participating mental health professionals accepted the tool (55.4% agreement, 33.9% full agreement), found it appropriate (64.6 % agree, 25.5 % fully agree) and feasible (55.9 % agree, 25.2 % fully agree). Similar results were obtained for the providers' assessment of need (46.5% agree, 15.7% totally agree), opportunity (57% agree, 28.9% totally agree), capability (50.9% agree, 44.1% totally agree), and motivation (48.8% agree, 23.4% totally agree) to use the sheet. Furthermore, motivation was the most important positive determinant of all three implementation outcomes.

Conclusion: The psychoeducation sheet about dementia grief might be a new helpful, additional tool used by mental health care providers to educate patients in dementia caregiving life circumstances.

ID: 127

Abstract Type: Workshop

Topics: Relationships and connection, Networks and compassionate communities

Keywords: Green/social prescribing, nature interventions, palliative care, grief support, caregivers

"What if our last breaths could be breathtaking?": A "walkshop" exploring parks/nature connection in palliative and grief care

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Target Audience: Palliative and grief care providers including: medical, nursing, spiritual and social workers, occupational/recreational/physical therapists, counsellors/psychologists; as well as community planners, developers, organizers, advocates and supporters.

Learning Objectives: Informed by Healthy-Parks Healthy-People, Green-Social Prescribing and Compassionate Communities movements, parks/nature have been found to play a role in quality of life at end-of-life, in palliative care, grief and memorializing. This session seeks to examine the meaning, as well as the realities, of connecting people and places that are forever changing in the seasons of life and cycles of nature. Here we ask, *how can positive nature experiences be facilitated for people in palliative and grief care?* We will uncover the necessary ingredients across health and park sectors, from professional and community sites of intervention. Ultimately, in this "walkshop" [a workshop with an immersive nature walking activity], participants will explore the guiding question *"What if our last breaths could be breathtaking*?" Specific "walkshop" objectives are to:

1) Learn about the evidence and practical activities for nature connectedness that contribute positively to palliative and grief care.
2) Discuss and directly experience nature connection, exploring the distinct aspects of nature contact and connectedness.
3) Feel reconnected to nature and inspired to facilitate nature connection for people experiencing palliative and grief care.

Workshop Format: In this "w*alkshop*" participants will both learn about action research discoveries and immerse themselves in their own personal discoveries of outdoor/nature connectedness for people experience palliative care, in grief/mourning and memorializing. Discussion of nature connectedness and interests will start the session. Results and outcomes of a decade-long intersectoral, collaborative research program will be shared through presentation, documentary film and storytelling. An immersive nature walking experience, outside, at the nearby Ringgepark (a short 2-minute walk from Kornhausforum, the main conference venue) will follow. Enlivening the lessons learned in presentation, dialogue and discussion, our walk will concentrate on an exploration of key aspects of nature connectedness (including sensory awakening, nature companioning/interpretation and nostalgia/memory making). Participants can prepare for a breathtaking, immersive session.

ID: 128

Abstract Type: Oral presentation

Topics: Policy and advocacy, Artistic and creative approaches

Keywords: Politic, National Policy, Advocacy, Election, Public Awareness

Bridging policy gaps in palliative care through political engagement: an action learning case study in Thailand

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Background: While Thailand possesses limited palliative care (PC) policies addressing advance directives, pain management, and home visits. Significant gaps remain, including community-based support, education, and end-of-life literacy. Due to the limited political attention to these crucial areas, the author explored the impact of direct political engagement in advancing public health palliative care policy.

Objectives: 1) elevate PC on the national agenda, and 2) raise public awareness on PC and good death issues.

Methods: This action-learning case study details the author's candidacy for the Thai parliament with the Move Forward Party (MFP), integrating PC as a campaign plank among 300 policy proposals, such as community PC center, medical equipments for PC home ward, good death act, etc. Leveraging my writing and cartooning skills and also years of experience in compassionate communities facilitator and project manager. Articles and artworks promoting PC policy were published throughout the campaign. Prime minister candidate presented good death policies in between debate and interviews events.

Results: 1) PC policies resonated with voters in healthcare, community work, and patient/caregiver sectors. 2) PC policy became a cornerstone of the platform, adopted by the government formed. Now the minister of the public health focus more on community based palliative and hospice care policies. 3) Public awareness and demand for PC, good death practices, and Medical Assisted in Dying (MAiD) increased, with death and end-of-life discussions becoming more normalized.

Conclusion: This case study suggests the potential of political engagement to expedite PC policy change and public discourse. However, political engagement opportunity of advocators may depends on national and local political context such as openness of political parties and interest of advocators. Action learning still in the process. The broader applicability of this approach, its limitations, and its long-term sustainability would be explored in near future.

ID: 129
Abstract Type: Poster

Topics: Artistic and creative approaches

Keywords: creative approaches, music therapy, bereavement, systematic review, informal carer

A creative approach to tackling complicated grief: the role of music therapy in protecting against risk factors

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Background: The research evidence base on bereavement support interventions is underdeveloped. Moreover, components of existing bereavement support interventions rarely map to the modifiable risk and protective factors for complicated grief. This presents uncertainty on the best model of care aligning to a public health approach to bereavement support. Arts-based therapeutic approaches, and notably music therapy, may be particularly useful in addressing the risk and protective factors of complicated grief. The current research in this area is however disparate and disconnected, with the need for a comprehensive review.

Objectives: To synthesise and critically evaluate the international evidence base for music therapy with adult informal carers of individuals with life-threatening illness at pre- and post-bereavement, and to map components of existing interventions on to established risk and protective factors for complicated grief.

Design: A Joanne-Briggs Institute mixed-methods systematic review.

Methods: Databases (MEDLINE, EMBASE, PsycINFO, RILM Abstracts of Music Literature, CENTRAL and CINAHL) were searched from 1998 to July 2022. The quality of both quantitative and qualitative studies was assessed using critical appraisal tools and data extracted. Quantitative data were described narratively and qualitative data were pooled using meta-aggregation. Synthesised findings were mapped to established risk and protective factors for complicated grief.

Results: A total of 34 studies were included in the review, published between 2003 and 2022. The quality of the quantitative studies was low-medium, with a higher quality of qualitative research identified (medium-high). Synthesised findings of outcomes and mechanisms of change mapped across established risk factors for complicated grief such as depression, anxiety, family conflict at end-of-life, poor perceived social support, early non-acceptance of loss, and difficulty accessing positive memories; and protective factors including higher spirituality, participating in work, and perceived preparedness for death.

Conclusion: There is a dearth of high-quality clinical trials in this area, which limits the conclusions which can be drawn on the benefit of music therapy as a bereavement support intervention. However, the rich qualitative research in particular identified mechanisms of change in existing interventions which mapped to a myriad of risk and protective factors of complicated grief.

ID: 130
Abstract Type: Poster

Topics: Networks and compassionate communities, Educational approaches

Keywords: dementia, public perceptions, adolescents, communities, public health

Developing dementia-friendly communities: A scoping review to understand adolescent knowledge and attitudes towards dementia

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Queen's University Belfast, United Kingdom

Background: Dementia often precipitates societal stigmatisation and exclusion, underscoring the urgent need for dementia-friendly communities. Embracing a public health approach to dementia includes adopting a life-course perspective to enhance overall societal awareness of dementia. This scoping review focuses on adolescents as critical contributors to developing supportive communities for individuals living with dementia. Currently, there is a paucity of evidence in this area.

Objectives: This scoping review represents a novel effort to identify and synthesize extant literature on the knowledge and attitudes of adolescents regarding dementia.

Design: A Joanne-Briggs Institute scoping review.

Methods: Four bibliographic databases—MEDLINE, PsycINFO, EMBASE, and CINAHL—were searched. Inclusion criteria encompassed qualitative and quantitative studies exploring the knowledge and attitudes of adolescents (aged 10-19) toward dementia. Rigorous screening processes were applied, utilizing JBI tools for data extraction. The synthesis reported i) adolescent knowledge and attitudes and ii) interventions.

Results: The review included 19 publications, which revealed that adolescents possess relatively limited objective knowledge of dementia. Despite this, their attitudes generally tend towards neutrality or positivity. A notable finding is that adolescents with familial exposure to dementia often held predominantly negative attitudes. The presence of family members with dementia alongside gender emerged as influential factors shaping both knowledge and attitudes. Particularly promising were interventions involving direct interaction with individuals living with dementia, indicating a potential avenue for public health-driven initiatives to enhance attitudes and awareness.

Conclusions: This review contributes to a growing body of literature on adolescent knowledge and attitudes towards dementia. The findings underscore the importance of a public health approach in shaping adolescent attitudes as a crucial step toward creating dementia-inclusive communities. By integrating adolescent perspectives into public health strategies, we can collectively work towards fostering understanding, reducing stigma, and building a more compassionate and informed society.

ID: 131
Abstract Type: Poster

Topics: Death and grief literacy, Research methods

Keywords: death literacy, death literacy index, content validity, DLI

An exploration of the content validity (relevance, comprehensiveness, and comprehensibility) of the Death Literacy Index in the UK

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Background: Death literacy is an important aspect of a new public health approach to palliative care and refers to the skills and capacities necessary to navigate and make informed decisions about death-related matters. The Death Literacy Index (DLI) allows for the exploration of current levels of death knowledge and skills within communities i.e., 'death literacy', and how these can be enhanced under public health care initiatives. The DLI was developed in Australia and has reported good psychometric properties across several international evaluations. In the UK, the DLI has evidenced good structural, convergent and discriminant validity. However, the content validity of the DLI within the UK has yet to be formally assessed.

Objectives: The aim of this study was to evaluate the DLI for content validity, focusing on the relevance, comprehensiveness, and comprehensibility in a UK population.

Design: A cognitive-interview study utilising a think-aloud technique

Methods: Fifteen cognitive interviews were conducted with members of the public across the UK, with participants asked to complete the DLI while voicing their thought processes aloud. This was followed by a short semi-structured interview schedule. The interviews were conducted online, and initially coded for any issues present using a coding framework based on the previous literature. Deductive thematic analysis was used to analyse the semi-structured interview data.

Results: Overall, the index was positively received by participants and opened up opportunities to expand comprehension of death processes and their access to services. There were issues identified with a small number of items. Participants also highlighted certain aspects of death literacy which they felt were missing and reported issues with use of jargon and presentation of the scale.

Conclusions: The DLI potentially has a number of uses in supporting practitioners in the UK aiming to advance the public health approach to palliative care. The current study highlights a number of areas where the DLI could be strengthened so that it is more attuned to the UK population.

ID: 132
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving

Keywords: family support, faith, acceptance of illness, dying, culture

Acceptance of illness and worry about dying and their association with faith and family support among advanced cancer patients

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Background: Advanced cancer poses multifaceted challenges that extend beyond the physical realm, encompassing psychological, social, and spiritual dimensions. The Filipino culture is characterized by strong familial bonds and deep-rooted faith, which are integral to the coping mechanisms of individuals facing life-threatening illnesses. Understanding how these cultural values influence the acceptance of illness and worry about dying is crucial for providing culturally sensitive and effective palliative and end-of-life care.

Objective: The study aimed to determine the independent associations of acceptance of illness and worry about dying with various sociodemographic & psychological characteristics, family support, and faith factors among advanced cancer patients.

Method: This is a cross-sectional study among 195 advanced cancer patients seen at the Cancer Institute of a major hospital in Metro Manila, Philippines. Participants completed the Functional Assessment of Cancer Therapy (FACT) and Hospital Depression and Anxiety Scale (HADS) questionnaires. Separate univariate analyses using the Chi-square test were performed for acceptance of illness and worry about dying.

Results: The majority (87.2%) of the sample accepted their illness, and many (41.6%) were not worried about dying at all. Having a college education, good emotional support from family, finding strength in one's faith/spiritual beliefs, and having one's faith/spiritual beliefs strengthened by difficult times were significantly associated with acceptance of illness. Finding strength in one's faith/spiritual beliefs and knowing that things will be okay even during difficult times were significantly associated with not worrying about dying.

Conclusion: To our knowledge, this is the first study that examined the association between faith, family support, acceptance of illness, and worry about dying among Filipino advanced cancer patients. The findings can inform healthcare professionals about the importance of incorporating spiritual and family-centered interventions into the care of advanced cancer patients. This may include integrating faith-based support or involving family members in the care process.

ID: 133
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, Death and grief literacy

Keywords: Minoritised communities, resource-poor, death literacy, advance care planning, inequity in access

Celebrating Life: An innovative community engagement project with minoritized ethnic populations living in areas of socio-economic deprivation in North London: A Service Evaluation

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Background: In the UK, access to palliative care is inequitable, disproportionately affecting global majority communities who are 16% of the UK population (2021).

Aim: The Celebrating Life project is a public health approach to an innovative community engagement initiative. In conversational workshops, the project explores community members perspectives and concerns about their health and wellbeing towards the end of life.

The objective is to promote the knowledge that global majority communities need to gain access to, and make informed choices about, end of life and after death care in the context of their death and bereavement systems.

The service evaluation aims to explore the usefulness of this project in increasing knowledge of palliative care, of care planning and of hospice services.

Design: In two local community centres in North London, 8 workshops were facilitated to encourage reflection on what matters most, and who and what informs treatment choices in advancing frailty and increasing symptom burden towards the end of life.

Methods: De-identified qualitative data was collected with participant consent to develop themes. The project was facilitated by research nurse with the approval of local community engagement manager.

Results: Eight workshops were undertaken (n=185) from July-November 2023. Global majority populations are filial cultures, with male led but family-based health decision making. Death conversations are generally avoided. There is stigma around morbidities like cancer and the use of morphine as treatment, contributing to late disclosure. Institutional mistrust is pervasive, exacerbated by a belief in systemic racism. Poor English language skills made participants feel "invisible". Family caregiving has a gendered lens negatively biased against women. Robust psychological and practical support for family care givers was considered very important in advancing disease. Advanced Care Planning (ACP) discussions are best facilitated with a trusted, ideally race concordant professional, in a family-based dyad.

Conclusion: Ill-health and death are a psycho-spiritual process (not event), happening in a social context, for global majority populations. 98% participants found the workshops very useful in sharing their views and improving their knowledge of palliative care and Marie Curie services. It is recommended that further workshops are undertaken, and the role of a link worker be explored to build trust and support family caregivers.

ID: 137
Abstract Type: Poster

Topics: Educational approaches

Keywords: end-of-life care, neurology, Philippines, training, End-of-life Professional Caregiver Survey

Educational approaches toward teaching palliative care to non-palliative care physicians

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Background: The Philippines was considered one of the worst places to die for having very few palliative care specialists capable of providing quality end-of-life care.

Objectives: This study aimed to determine the end-of-life (EOL) competence of neurologists in a training hospital in the Philippines towards developing educational approaches for teaching palliative care to other specialists.

Methods: An online survey was conducted among neurologists and residents-in-training in an academic hospital using the End-of-life Professional Caregiver Survey (EPCS), which covers eight domains of the palliative care guidelines, including spiritual and cultural issues; ethical, professional, and legal principles; organizational skills; and attitudes, values, and feelings of health care professionals. Statistical analysis included frequencies, chi-square statistics, and logistic regression.

Results: Forty neurologists completed the survey. Seventeen percent reported they had basic training in palliative care. Highest scoring items included being comfortable in starting and participating in code status discussions, communicating with health care professionals about the care of dying patients, being able to deal with one's feelings related to working with dying patients, being present with dying patients, and recognizing patients who are appropriate for hospice referral. The lowest-scoring items included knowing how to use non-drug therapies in the management of symptoms, addressing patients' and family members' fear of addiction to pain medications, providing grief counseling for staff, and addressing requests for assisted suicide. The EPCS total score and Patient and Family Centered Communication subscale were significantly higher in participants with prior EOL basic training than those without. There were statistically significant associations between previous basic EOL training and discussing advance directives and specific issues like tracheostomy and gastric tube placement early in the course of the disease.

Conclusion: The EPCS mapped which knowledge, attitudes, and skill areas need to be included in the educational approaches toward teaching palliative care to non-palliative care physicians.

ID: 138
Abstract Type: Poster

Topics: Policy and advocacy

Keywords: policy, advocacy, Quality of Death Index, Philippines, end-of-life care

Policies and advocacy toward upgrading the 2015 Philippine status from being the 3rd worst place to die in the world (78th out of 80 countries) to 38th place in the cross-country comparison of expert assessments of the Quality of Death and Dying 2021

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Background: In 2014, the World Health Assembly (WHA) approved the Resolution urging national governments to carry out actions to develop palliative and end-of-life care.

Objectives: To advocate for and develop policies and actions toward advancing palliative and end-of-life care in the Philippines.

Methods: The national movement to promote palliative and hospice care started in the early 2000s. In 2012, the Palcare Hospice Foundation organized the First Regional Conference on Palliative and Hospice Care. In July 2013, a House Bill entitled "Hospice and Palliative Care Act: Integrating Palliative and Hospice Care into the Philippine Health Care System" was filed in Congress. The bill passed the lower house in January 2015.

The 2015 Quality of Death Index has listed the Philippines, out of 80 countries, as one of the worst places to die. The country scored poorly regarding the quality of end-of-life care available.

In December 2015, the Department of Health (DOH) issued an Administrative Order, the "National Policy for Palliative and Hospice Care in the Philippines."

Results: In 2019, two landmark bills were enacted: the National Integrated Cancer Control Act (NICCA) and the Universal Health Care (UHC) Law. In 2021, The Department of Health-Manual of Operations, Procedures, and Standards (DOH-MOPS) for the National Palliative and Hospice Care Program was launched. As a result of these efforts, in 2021, the global ranking of the Philippines in the Cross Country Comparison of Expert Assessment of the Quality of Death and Dying rose to 38th.

In November 2023, the Department of Health (DOH), in partnership with Jose B. Lingad Memorial General Hospital (JBLMGH), led the development of the first Philippine Clinical Practice Guideline (CPG) on palliative and end-of-life care (PEOL) for adult patients with cancer. This local CPG will be used for policy and benefit package development and disseminated widely through various channels.

Conclusion: This year, 2024, will see the roll-out of primary care physicians nationwide training on palliative and end-of-life care using the DOH-MOPS and the Philippine CPG. The DOH's vision is to provide comprehensive cancer care and optimized cancer survival by 2025. For those who will not be able to survive cancer, it is hoped that the trained primary care physicians will still be able to render quality end-of-life so that most seriously ill Filipinos will die in comfort and with dignity.

ID: 139

Abstract Type: Oral presentation

Topics: Death and grief literacy, Educational approaches

Keywords: Advance care planning, general practice, palliative care, communication, older people

Information meetings stimulate older people to talk about their wishes at the end of life

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Background: Information meetings are a way to inform older people about end-of-life care, increase awareness, and to prepare for advance care planning (ACP). Meetings are organized by general practitioners (GPs) inviting their own patients or by other organizations (e.g. hospice, welfare organization) targeting older people in general.Objectives To assess whether information meetings increase ACP conversations with the GP and relatives and advance directives in older people, and to explore which factors are associated with having ACP conversations with the GP in response to a meeting.

Design: A pre-post interventional study was designed with questionnaires before (T0), at the end (T1), and 6 months after the information meeting (T2).Between February 2021 and December 2022, 124 information meetings were organized, of which 59 by GPs and 65 by other organizations.

Methods: 2,230 older people attended a meeting and filled out questionnaires directly before and after the meeting, with 1,212 of them also completing a questionnaire six months later. Descriptive statistics and logistic regression analyses were done.

Results: Six months after the meeting (T2), 26% of attendees had had an ACP conversation with their GP in response to the information meeting. Age (OR 1.05; CI 1.03-1.08) and having discussed wishes with a physician before the meeting (OR 2.53; CI 1.82-3.51) were significantly associated with having had an ACP discussion with their GP. Type of meeting (GP vs other), sex, and having recorded or discussed wishes with relatives before were not associated. Further, more older people discussed their wishes with relatives (T0: 59%; T2: 83%) and recorded their wishes (T0: 38%; T2: 52%) at T2.

Conclusion/discussion: Information meetings about end-of-life care stimulate older people to have ACP conversations with GPs and relatives and to record wishes. The type of meeting, by GPs or others, does not affect ACP conversations with the GP in response to the meeting. ACP ideally includes regular reflection on wishes; the meetings stimulate regular ACP conversations with the GP.

ID: 140

Abstract Type: Oral presentation

Topics: Death and grief literacy, Educational approaches

Keywords: Advance care planning, migrants, palliative care, communication, older people

Information meetings on end-of-life care for Turkish and Moroccan older people

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Background: Culturally sensitive communication with Turkish and Moroccan older people about end-of-life care is important. Factors such as a language barrier, taboos or beliefs about dying may play a role. Information meetings can increase awareness and knowledge of end-of-life care and stimulate ACP.

Objectives: To explore the experiences with information meetings about end-of-life care and to assess whether information meetings increase ACP conversations with the GP and relatives in Turkish and Moroccan older people.

Design: A pre-post interventional study was designed with questionnaires before (T0), at the end (T1), and 6 months after the information meeting (T2). The information meetings were part of a larger project; a standard presentation was used. Current meetings were hosted by experienced health educators (partly) in Turkish or Arabic language.

Methods: In 19 information meetings, 70 Turkish and 95 Moroccan people completed questionnaires before and/or directly after the meeting, with respectively 29 and 11 of them also completing a questionnaire 6 months later. Descriptive statistics were done.

Results: Of Turkish and Moroccan participants, 91% and 77% indicated that the information meeting met, and 6% and 22% somewhat met, their expectations. The majority of Turkish and Moroccan participants rated the choice of topics (91% and 87%, respectively) and the clarity of information (94% and 81%, respectively) as (very) good. None of the Turkish and 2 in 11 Moroccan participants reported to have had ACP conversations with their GP in response to the meeting at T2. Both Turkish (T0: 10%; T2: 38%) and Moroccan (T0: 20%; T2: 50%) participants discussed their wishes more with relatives at T2.

Conclusion: Information meetings stimulate Turkish and Moroccan older people to have ACP conversations with relatives, but show little effect on conversations with their GP. In general, Moroccan and especially Turkish older people were satisfied with the information meetings. A standard presentation with all important topics can be used.

ID: 142 / 143

Abstract Type: Oral presentation and Poster

Topics: Networks and compassionate communities, Educational approaches

Keywords: palliative care, school project, education, lesson, public relations

"Palliative Care goes School" - Results from a Project for Upper School Classes in Vorarlberg

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Background: To find out about the attitude of young people towards Palliative Care and Euthanasia a survey was conducted among upper class pupils in Vorarlberg. The school visit of a multiprofessional palliative care team was evaluated through a questionnaire.

Aims: By arousing interest for palliative care work, pupils should experience that assisted suicide is not the only answer to severe illness. The insight into the daily work of a palliative care nurse or a physician might influence the perception about Palliative care.

Methods: A questionnaire was filled out a week before (T0) and a week after (T1) the school visit of a palliative care team. The evaluation of the survey (partly questions that allowed personal comments, partly those with a rating scale) was done by the Vorarlberg university of applied sciences.

Results: A total number of 776 T0 and 516 T1 sheets were completed. The age of the pupils ranged from 15 – 21 years. 64% (T0) had experiences with loss. The question „Should assisted suicide only be permitted in individual cases?" was rated by 41,3% students with „sure" und „very sure" in the T0 questionnaire. After the school visit this number increased to 48%.

The main associations with Palliative Care work before the lecture were *death and dying, emotional drain* and *grief*. After the visit these terms were chosen less often, but positive associations such as *hope, symptom control, to live intensely, fulfilling work* and *humor* gained numbers. The difference in all these terms was statistically significant.

Conclusion: An introduction into practical palliative care work showed a change in the attitude towards assisted suicide. The terms associated with palliative care modified after the visit: much more positive expressions like *hope, symptom control* and *humor* were mentioned.

ID: 144

Abstract Type: Oral presentation

Topics: Relationships and connection, Research methods

Keywords: Story telling Café; End of Life; Intergenerational; Intercultural; Narrative Group Methdods

Caring Cultures at the End of Life. Storytelling Cafés about End of Life as Palliative Care Research Method

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Background: Care cultures encompass a diversity of mindful caring attitudes and activities as well as social practices in families, teams, organizations, communities or the society as a whole. Many students entering nursing education encounter dying people for the first time during their first internships. They are not always well prepared for the emotional impact a death can have on them. The project aims to open up a space for them to share and reflect on their experiences through narratives.

Aim: The project aims at generating knowledge about cultures of care at the end of life and about dying as a multidimensional process with the participation of students and Citizen Scientists in an exchange between different age groups and different cultural groups, including the category of gender.

Research design and process: The participatory research project brings together nursing students and old people with and without dementia. They tell each other about their end-of-life experiences in storytelling cafés. The storytelling cafés take place in public organizations such as libraries and museums, but also in nursing homes. The Cafés are recorded and transcribed and we performed a narrative and a thematic analysis of the data.

Findings: At the present time, we have performed 13 storytelling cafés in different settings bringing together nursing students and older people with different cultural background. All participants engaged voluntarily in the narrative research. Those who did not want to tell acted as observers. The storytelling cafés made it clear that all participants, older people and students alike had (more or less) experience with dying, death and mourning, whether in their private or professional lives. The cafés offered an opportunity to share and reflect on the experiences in a trustful and empathic atmosphere. Doing gender is apparent in the storytelling cafés and needs to be facilitated. Telling a story about end of life to another generation is comforting and has a spiritual dimension. Cultural differences can be overcome in the storytelling café. Some ways to deal with death and dying are alike in India and in specific European regions. We have made good experiences with storytelling cafés about end of life as narrative group methods in palliative care.

ID: 145
Abstract Type: Poster

Topics: Relationships and connection

Keywords: Capabilities, Nursing, Home-based care, Palliative care, Narrative inquiry

How to produce a health-oriented nursing practice in home-based palliative care? Results from a narrative inquiry

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Background: Home-based palliative care nursing has been critiqued for its focus on biomedical parameters, such as pain or end-of-life symptom management. This focus tends to maintain nursing practice at odds with patient aspirations, thus limiting their ability to live life to the fullest until death. Despite this clinical focus, the aim of nursing discipline and practice revolves around health throughout all stages of life. Thus, the connection between palliative care nursing and health-oriented practices needs to be contemplated to support its development from a nursing perspective.

Objectives: The purpose of this presentation is to describe mechanisms of health-oriented nursing practice in home-based palliative care so that dying people can live the life they value until death.

Design: An iterative methodology combining theoretical and empirical work was conducted, in coherence with a pragmatic constructivist epistemology and a systemic model of nursing practice. The theoretical component is based on Amartya Sen's capability approach. Capabilities are defined by Sen as the set of effective freedoms people possess to live the life they have reason to value. Based on Sen's ideas, we proposed that health-oriented nursing practice in home-based palliative care can be conceptualized as the conversion process of resources into health capabilities. This idea was explored with the empirical component of this project. A descriptive-interpretive qualitative design was conducted. First, three stories were co-constructed with nurses working in home-based palliative care. A fourth story recounted the author's emerging reflections in relation to his own clinical and research practice. Those four stories were analyzed with an analytical questioning process to describe mechanisms of health-oriented nursing practice.

Results: Four nursing mechanisms that tend to create capabilities for dying people to live the life they value until death were described: 1) navigating between a life valued and norms, 2) seeing a dying person as both capable and vulnerable; 3) reflexively engaging with one's practice, and 4) being creatively present.

Conclusion: These findings suggest that home-based palliative care nursing engages reflexivity, reciprocity, and creativity in relation to the dying person. For the discipline of nursing, a capability lens reveals how nursing practice can engage with the lives valued by dying people, until their death.

ID: 146
Abstract Type: Oral presentation

Topics: Artistic and creative approaches

Keywords: Mindfulness, Compassion, Art-based Therapy, Burnout Prevention, Resilience

Caring for caregivers: processing loss and building sustained resilience with Mindful Compassion Art-based Therapy (MCAT)

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Background: Protecting the mental health of healthcare workers is an urgent global public health priority. Healthcare workers, especially those immersed in palliative care, are prone to burnout due to the intense emotions associated with end-of-life caregiving.

Objective: This paper examines the efficacy of a novel, multimodal, and group-based Mindful-Compassion Art-based Therapy (MCAT) that integrates reflective self-awareness with creative emotional expression for protecting healthcare workers' mental health.

Design: A dual-arm open-label waitlist randomized controlled trial was conducted. A total of 56 healthcare workers were recruited from the largest homecare hospice in Singapore and randomized to the immediate-treatment condition of a standardized 6-week, 18-hours MCAT intervention (n=29), or the waitlist-control condition (n=27).

Methods: Self-administered outcome measures on burnout, resilience, emotional regulation, self-compassion, death attitudes, and quality of life were collected at baseline, post-intervention/second-baseline at 6weeks, and follow-up/post-intervention at 12weeks.

Results: Results from mixed model ANOVAs reveal that treatment group participants experienced significant reduction in mental exhaustion, as well as significant improvements in overall emotional regulation, nonreactivity to intrusive thoughts, approach acceptance of death, and afterlife belief as compared to waitlist-control immediately after MCAT completion. Effect sizes of these impacts ranged from medium to large (η^2=0.65 to 0.170). Results from one-way ANOVAs further reveal that the treatment gains of reduced mental exhaustion and increased emotional regulation were maintained among treatment group participants at 12-weeks follow-up compared to baseline, with new benefits identified. These include increased ability to observe and describe one's experiences, elevated overall self-compassion, greater mindful awareness, enhanced common humanity, and better quality of life. Effect sizes of these impacts were large (η^2=0.128 to 0.298).

Discussion: These findings reflect the robust effectiveness and positive residual effects of MCAT promoting mental wellness among healthcare workers. Experiential narrative of MCAT's participants will be shared to illuminate the inner workings of this psychotherapeutic for enhancing end of life care provision via professional self-care. Finally, the applicability of MCAT in larger and more diverse caregiving contexts are discussed.

ID: 147
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving

Keywords: Non-death loss, Rehabilitation, Recovery needs, Stroke survivors, Systematic reviews

Psychosocial Rehabilitation Trajectory of Stroke Survivors (PReTS): An overview of systematic reviews of recovery needs and non-death losses

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Background: In the aftermath of stroke, survivors experience multiple non-death losses that alter numerous aspects of their lives not limited to decreased functional capacity, restricted mobility, identity uncertainty and relational discord. During rehabilitation, they navigate through these losses and endeavour to move forward with life despite their debilitating impacts. However, the psychosocial processes that survivors adopt for coming to terms with and rising above their losses during this challenging period are yet to be understood.

Objectives: This overview of systematic review critically consolidates and appraise the psychosocial recovery needs of stroke survivors and proposes the development of a trajectory that encapsulates their journey from illness to rehabilitation.

Design: This overview adhered to the PRISMA guideline and employed the PICo (population, phenomena of interest, context) framework to screen for relevant systematic reviews for analysis.

Methods: Six major databases were searched, including Academic Search Premier, CINAHL, Global Health, Medline, PsychArticles, and PsychINFO between 2010 and 2020. The literature search identified 1302 articles. Of these, 52 articles were selected for full-text screening and reviewed for methodological quality leaving a total of 18 SRs for data analyses using thematic synthesis.

Results: Data synthesis revealed 18 themes that were further organized into six conceptual categories: (1) The unfamiliar body (2) Compassionate healthcare system, (3) Holistic rehabilitation, (4) Intrapersonal strength, (5) Interpersonal relations, and (6) Thriving forward. The research process allowed for the development of the Psychosocial Rehabilitation Trajectory of Stroke Survivors (PReTS) model that recognizes the multiple stroke-related losses and emphasizes the essentiality of addressing psycho-socio-emotional and spiritual needs alongside physical impairments.

Conclusion: Aside from physical recovery, current rehabilitation practices have yet to address the psychosocial impact of stroke. The PReTS model highlights survivors' losses, recovery journeys and most specifically, their psychosocial needs, and serves to inform and advance holistic and wellness recovery research.

ID: 148 / 113
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Research methods

Keywords: Palliative care, qualitative interviews, needs assessment, home deaths, support interventions

A 'buddy' as an additional resource in the care of patients with advanced, incurable illness and their families: Findings from qualitative interviews with patients, bereaved relatives and health and social care professionals

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Background: The unmet needs of people who are being cared for at home and who wish to die there and their families, are very high and the need for support is very complex. Although structures and services exist to support patients and their families, these services do not reach people in a timely manner or at the time when they are most needed.

Objective: To define, on the basis of specific experiences, elements of a possible complementary support concept to facilitate dying at home.

Design: Qualitative interview study as part of a larger mixed-methods study called "Dying at Home".

Methods: Qualitative triangulation of data was conducted from national individual interviews (patients and relatives, n = 45) and focus group discussions (health and social care professionals, n = 22). Qualitative content analysis of the verbatim transcribed interviews was carried out using MAXQDA©.

Results: Participants reported a lack of a contact person who could provide real-time information about support services, initiate appropriate end-of-life care at home, provide emotional support and be easily accessible - a so-called 'buddy'. Differences in support needs were also found between groups (e.g. cancer/non-cancer patients). Communicating one's needs was also identified as a reason for not using services.

Conclusion: Our findings show the wide range of elements that can be used to address unmet emotional, informational, appraisal and instrumental needs in end-of-life care at home. Additional and proactive support is needed to consolidate existing health and social care structures where they are unknown or insufficient to organise care according to families' needs. The concept of a 'buddy' for people with advanced,

incurable illness could be helpful here, helping them to navigate and access the different services and encouraging them to identify their own needs and seek help. It is important that the "buddy" is accessible at a low threshold and, as a contact person, shares his/her knowledge in real time if possible.

Making it happen: Since 1 May 2023, the project "A buddy for the seriously ill and their relatives" has been funded by the Deutsche Fernsehlotterie: https://buddy-koeln.de/. From 2024, the project will be evaluated by the Department of Palliative Medicine with funding from the Marga and Walter Boll Foundation.

ID: 149
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, Death and grief literacy

Keywords: bereavement support, palliative care, implementation science, healthcare professionals, evidence-based care

Implementability of an evidence-informed BEereavement SupporT pathway in Swiss specialized palliative care (BEST for Family): Pre-implementation analysis of palliative care staff perceptions

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Background: Bereavement support for families is an essential part of palliative care (PC) services. To provide services based on the best available evidence and guidance, an evidence-informed bereavement support pathway and a tailored implementation plan were developed in close collaboration with two Swiss PC services.

Objectives: To assess PC staff's (1) self-perceived skills in and quality of family care, (2) self-reported attitudes towards evidence-based practice, and (3) perceptions of the acceptability, appropriateness, and feasibility of an evidence-informed bereavement support pathway prior to its implementation.

Design: Cross-sectional baseline survey that is part of a mixed-methods study with multiple time points (before, during and after implementation).

Methods: Data were collected between September and December 2023 from nurses, physicians, chaplains, psychologists, and others working clinically in specialized PC services at two major urban teaching hospitals in German-speaking Switzerland. Of the 62 eligible PC staff, 39 participated (63%). The selection of study endpoints was guided by Proctor's Conceptual Model of Implementation Research. Acceptability, appropriateness, feasibility, and self-reported attitudes towards evidence-based practice (implementation outcomes) as well as self-perceived skills in and quality of family care (service outcomes) were measured using psychometrically validated rating instruments, and analyzed using non-parametric inferential statistical tests.

Results: Of the 39 participants, 28 (72%) were nurses and 6 (15%) were physicians. Skills in and quality of family care achieved a median score of at least 75% of their respective instrument range, and the pairwise correlations between them were moderate to strong (Spearman's rho > 0.48; $p < 0.01$ for all pairs). Acceptability, appropriateness, and feasibility reached a median of at least 69%, and acceptability and appropriateness were positively correlated (Spearman, $p < 0.01$). Attitudes towards evidence-based practice achieved a median score of 64%, with physicians reporting higher scores than nurses ($p < 0.05$, Dunn-Bonferroni, Kruskal-Wallis).

Conclusion: Our findings suggest that PC staff are well prepared and open towards structured bereavement support to families, but potentially more critical of evidence-based care. The actual implementation of the pathway and its success will require careful evaluation.

ID: 150
Abstract Type: Oral presentation

Topics: Death and grief literacy, Educational approaches

Keywords: Palliative care, South Asian community, Culturally and linguistically diverse, Death literacy, Educational Forum

Beyond borders: A community engagement approach to palliative care for multicultural communities

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Culturally and linguistically diverse (CALD) populations experience several barriers in accessing palliative care supports and services. Common barriers, including language, health literacy and differences in beliefs around death and dying, impact experiences of care and can often result in underutilisation of palliative care supports and services. This is especially relevant for the South Western Sydney Local Health District (SWSLHD) in Sydney, Australia, where 68% of families speak a language other than English at home, and more than half its residents (52.7%) born overseas, compared to the 33% national average.

This project aimed to use a community-based approach to increase dialogue about palliative care, including death and dying matters, among South Asian populations. It aimed to engage and educate South Asian community leaders on key areas, including the local healthcare system, with particular emphasis on the Palliative Care Service.

A mixed methods design was utilised. 3 Multicultural Health Officers (MCHOs) engaged in a User Experience (UX) workshop and identified South Asian populations across SWSLHD at greater risk of lower service use. In response, a 3-hour culturally specific educational forum, incorporating culturally appropriate storytelling and discussions on palliative care, was delivered to 40 South Asian community members and leaders. The forum was evaluated for changes in knowledge and understanding of palliative care among participants through pre-and-post surveys.

Three main themes from the UX Workshop informed the forum's agenda: (i) lack of awareness of palliative care and its services; (ii) family and support systems and (iii) faith and spiritual beliefs impacting on palliative care service utilisation. Evaluation of the forum reported 100% of participants having learned something new or valuable from the forum and the majority (77.8%) of participants reported increased confidence talking about and accessing information on palliative care and end of life.

The forum's use of personal storytelling, interactive discussions, and culturally sensitive approaches had a positive impact on increasing knowledge, skills, and value of palliative care among community members and leaders of South Asian origin. Replication of this culturally sensitive intervention is being undertaken, with a specific focus on expanding the work to include the engagement of younger South Asian community members to continue the conversation.

ID: 151
Abstract Type: Poster

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: Palliative care, Compassionate Communities, Libraries, Death Literacy

Compassionate Libraries: building compassionate communities with our local libraries

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Libraries are an essential component of the compassionate communities model. Their role as community hubs, providing a range of cultural, health and social programs, supports the nurturing of community life, with the role of librarians often likened to ad hoc social workers. Despite this, little has been done to engage libraries across the South Western Sydney Local Health District (SWSLHD) in Sydney, Australia, in developing compassionate communities.

This project aimed to build compassionate libraries by first equipping librarians across the SWSLHD with the knowledge and tools to support community members accessing information and resources regarding palliative care, illness, dying, death and bereavement.

A quasi-experimental design was utilised based on a 2020 report by the SWSLHD Palliative Care Service, which found all (6) surveyed council librarians believing education and training about palliative care, life limiting illnesses, death, and bereavement to be beneficial. In response, a pilot 2-hour educational palliative care workshop, incorporating local palliative care services, relevant case studies and the role of libraries in compassionate communities, was delivered to librarians from the local government areas of Camden, Narellan and Oran Park. The workshop was evaluated for changes in knowledge and confidence in supporting community members around death and dying matters among participants through pre-and-post surveys.

Four librarians from the Camden Community Libraries participated in the workshop. Findings included: (1) 100% of librarians strongly agreeing to being able to define palliative care in comparison to 28.6% prior to the workshop, (2) 100% increase in awareness and confidence of accessing information about SWSLHD palliative care services and (3) 66.7% feeling much more confident in having conversations about palliative care and end of life.

This workshop has helped develop the knowledge and skills librarians possess to offer greater support to community members accessing information about palliative care services. The strong engagement observed among librarians in this intervention advocates for further work in this area. The SWSLHD Palliative Care Service aims to extend this intervention to neighbouring libraries across the district and further look at developing and/or tailoring existing library programs to enhance the compassionate communities model.

ID: 153
Abstract Type: Oral presentation

Topics: Death and grief literacy

Keywords: Death Literacy, Death Literacy Index, Validity, Reliability

Death literacy as a basis for dealing with death and dying in German-speaking regions

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Background: Also in German-speaking regions, there are various initiatives to strengthen the understanding of death, dying, and bereavement as a natural part of life. The goal is to raise social awareness and to provide equal access for all to dignified support and care at the end of life according to their individual needs. One underlying prerequisite for this goal is death literacy, as it helps to understand death, dying, and bereavement more as shared social processes than medical phenomena. Therefore, coordinated local networking between civil society, the health system and politics is necessary. In Germany, palliative support points are an example of such networking structures. Additionally, there are several initiatives to improve death literacy, including school projects and last aid courses. Currently, their effectiveness has not been systematically evaluated, and there are no validated instruments for measuring death literacy in German-speaking regions.

Objectives: Development of a German-language version of the Death Literacy Index (DLI-German) to assess awareness and competence in dealing with dying, death, and bereavement within and outside the German health and social care system. The Index is also intended to be used for the evaluation of measures to improve death literacy.

Design and Methods: Translation and validation of the Death Literacy Index, as well as adaption to the health and social system in German-speaking regions. The applicability of the DLI-German for the evaluation of measures to improve death literacy is to be tested. Additionally, we plan to develop an internet-based tool for calculating the Index, including information on regional support services on death, dying, and bereavement.

Expected results and conclusion: An instrument for measuring death literacy in German-speaking regions is intended to map death literacy in society and to evaluate measures to increase it. The provision of the instrument as an online tool in combination with information on regional support services can contribute to improving death literacy.

ID: 154
Abstract Type: Poster

Topics: Research methods

Keywords: medication safety, deprescribing, oral anticoagulants, venous thromboembolism, secondary prophylaxis

Use and deprescribing of direct oral anticoagulants in palliative care

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Background: The risk of venous thromboembolism (VTE) and lung embolism (LE) is particularly high in palliative care (PC) patients, who often have multiple conditions with an elevated risk. While VTE/LE is associated with distressing symptoms such as pain and dyspnea, thromboprophylaxis can also increase the risk of bleeding.

In current clinical practice, direct oral anticoagulants (DOAKs) have gained importance as both therapy and prophylaxis.

Objectives: To provide a literature overview of DOAKs in PC, in the context of secondary prophylaxis of DVT and/or pulmonary LE and of the current practice in PC institutions in German-speaking Switzerland, Germany, and Austria.

Design: Qualitative expert survey with case vignettes

Methods: 1) Scoping review in Medline and Embase in order to identify recommendations for, and 2) an online survey among PC physicians and pharmacists to explore current practice regarding the use and deprescribing of DOAKs, in the context of secondary prophylaxis of DVT/LE in PC patients.

Results: We included 13 publications, with 10 reviews from Europe. Most recommendations were based on cancer-associated thrombosis. The decision to discontinue or avoid anticoagulation in PC should be based on shared decision making (11 publications), renal (11) and liver (9) function, life expectancy (8), bleeding risk (8), cancer type (7), thrombocytopenia (4), and nutritional status (3). 46% of publications consider the evidence base for DOAKs questionable, while 54% discouraged anticoagulant use at end-of-life altogether.

The survey was answered by 41 of 62 (66%) of experts. The majority (36/39, 92%), would generally consider secondary prophylaxis with a DOAK in the case of a previous DVT and LE in a cancer patient, and a life-expectancy of 3-6 months, provided there is no contraindication. Main reasons were the high risk of VTE recurrence and the benefit to the patient's quality of life. Substance of choice was apixaban (27/32, 84%). Discontinuation was considered with a life expectancy of $\leqslant$ 2 weeks (13/33, 39%) or a few days (12/33, 36%). Twentysix experts reported difficulties in decision making in case of TVT/LE in end-of-life care.

Conclusions: Experts showed a high readiness for the use of secondary prophylaxis of VTE/LE in PC patients and were open to consider DOAK, mainly due to a perceived high recurrence rate and symptom burden. The use as well as deprescribing of DOAKs in PC for primary and secondary prophylaxis as well as therapy still lacks evidence.

ID: 157
Abstract Type: Oral presentation

Topics: Relationships and connection, Technology and digital innovations

Keywords: Rapport, telehealth, community, palliative care

Building bridges with rapport: experiences during telehealth in palliative care

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Background: There was unprecedented growth of telehealth in response to the COVID-19 pandemic. However, there has been concern from health professionals about the possible disruption to developing rapport when using telehealth, particularly in palliative care, where rapport is considered essential to patient and family care.

Objective: This study was designed to explore patient, family, and palliative care professional's perspectives of rapport in telehealth encounters in the community.

Design: An Interpretive Description methodology was utilised, with the Theory of Human Relatedness providing the theoretical framework.

Methods: Data was gathered in two phases:

1. Semi-structured interviews with patients and family members who had received telehealth calls
2. Focus groups and individual interviews with health professionals working in palliative care using telehealth.

Data was analysed using Reflexive Thematic Analysis.

Results: The key finding from patients and families included relaxed interactions with rapport and uncomfortable interactions without rapport; all of which were related to the presence and skill of health professionals. From the health professionals the key findings identified the complexity of telehealth calls and the interpersonal skills needed to develop rapport.

The key outcomes of the study include the development of a conceptual definition of rapport for clinical interactions based on the patients and family findings. Along with an adapted "Model of rapport and relatedness" which highlights participants experiences of interactions characterised as Connectedness, Disconnectedness, and Pseudo-rapport.

This study adds important new knowledge about what constitutes rapport and how it is experienced during telehealth calls. This knowledge is useful for communicating to connect with patients and families.

Conclusion: Rapport via telehealth is a vital interpersonal skill that helps makes connections with patients and families at home. It requires health professionals to be present and reflexive. The implications for practice include that rapport via telehealth is achievable and teachable. Focus on reflective practice, and rapport specific telehealth education and training are recommended.

ID: 158
Abstract Type: Oral presentation

Topics: Policy and advocacy, Technology and digital innovations

Keywords: mHealth, mobile health, palliative care data management, Health Informatics, Digital Health, HMIS, DHIS2

Strengthening palliative care data Integration in national Health Management Information System (HMIS): The mobile Health surveillance story of data driven by compassion in Uganda

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Background: With the availability of palliative care services across 80% of its districts, Uganda is a leader in palliative care in Africa with specialist services provided since 1993 however there was lack of harmonized nationwide data collection and management. During the 2012 Health Management Information System (HMIS) review, the Ministry of Health included the data element "pain requiring palliative care" in the Outpatient and Inpatient Department registers. The indicator was included in the District Health Information System (DHIS 2) under the HMIS FORM 105: Health Unit Outpatient Monthly Report. This indicator was insufficient to measure the state of Palliative Care services in Uganda.

In 2020, Uganda initiated a pioneering endeavour to integrate palliative care data into the national HMIS.

Objectives: To harmonize national palliative care data collection and management within the HMIS.

Design: The initiative followed a multidisciplinary and collaborative design, incorporating key stakeholders in palliative care, public health, and health informatics in private and government institutions.

A technical working group was formed, periodic meetings were held, and tool drafting was done followed by pretesting, and approval by the Ministry of Health.

Methods: In May 2015,a pilot M-health (Mobile Health) palliative care surveillance project was initiated in four hospitals in Uganda. The palliative care providers were trained to use smartphones to collect several data elements on palliative care monthly. By 2019, 20 government and private not-for-profit hospitals were collecting palliative care data. The information obtained from the project provided evidence and a baseline for the HMIS Palliative Care tool.

Results: Palliative care tools were developed and added into the HMIS:

1. HMIS OPD 008 Unit Palliative Care Register
2. HMIS 105c Health Unit Palliative Care monthly report.

Over 50% of facilities offering palliative care in Uganda are reporting through the system and this has provided a more comprehensive understanding of palliative care services at facility, regional and national levels.

Conclusion: Uganda's journey signifies not only a successful integration of palliative care data into the National HMIS but a commitment to an enduring cycle of support, learning, and data refinement. By emphasizing the need for continuous support supervision and data quality assessments, Uganda continues to strengthen a sustainable model that can be emulated globally.

ID: 159

Abstract Type: Oral presentation

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: death literacy, systematic approch, community, multi-method, PDSA cycle

Improving Death Literacy in a Community: A systematic Approch

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Background: Dealing with severe illness, dying and bereavement is a major life issue for all of us, but often competencies can be improved, both in health and social structures as well as in patients, relatives and healthy people.

Objectives: To improve death literacy in a community by setting up a Plan-Do-Study-Act cycle.

Design: Based on longstanding hospice and palliative care experience, as well as studies on how the last year of life was perceived by bereaved relatives and what they felt was needed as additional support we have started (some completed, some ongoing) several interventions at different levels.

Methods: Multi-methods research by surveys, secondary data analysis, focus groups, in-depth-interviews.

Results: Networking projects: Setting up a caring community structure based on a palliative and hospice network together with political and civic support in the city.

Health and social care system projects: Implementation of the Surprise Question 12 months in addition to Patient Prompt Sheets, improvement of care of the dying in general wards and intensive care units, offering a communication training on the desire to die for professionals, volunteers and relatives, early integration of palliative care and coordination in multiple sclerosis, glioblastoma and bone marrow transplant patients.

Outreach projects: Setting up a “buddy” system for seriously ill people and relatives, last aid and bereavement support in the workplace, school projects on death, dying, bereavement and suicide.

Conclusion: Improving death literacy in a community can be approached at multiple levels combining innovative practice and scientific evaluation. As this is an ongoing process over decades, appropriate structures need to be put into place to make it independent of specific projects and individuals.

ID: 160

Abstract Type: Oral presentation

Topics: Relationships and connection, Social and structural determinants of death dying and grieving

Keywords: relational ethics, ethics, palliative care, equity, structural vulnerability

Using relational ethics to guide equity in public health palliative care

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Background: Evidence suggests that people experiencing inequities and who are highly marginalized (e.g., people impacted by racism, sexism, discrimination, stigma, mental illness, substance use issues, disability, and the effects of homelessness; also referred to as structurally vulnerable) often die alone, in pain, not receiving the care they need. Some research even points to individuals who are highly marginalized not feeling worthy of care. The need to consider equity in the context of palliative care has emerged but little attention has been paid to how ethical decision-making generally, and relational ethics, specifically, could provide guidance in the care of individuals who are highly marginalized who are on a palliative trajectory. Relational ethics offers a model of care and decision-making framework that emphasizes how clients, health care providers, and larger social structures are interwoven, and acknowledges that one’s background and relationships influence their choices. Relational approaches in the context of public health palliative care have the potential to provide a lens to better support the delivery of equitable care and change the discourse around how care is offered to individuals who are highly marginalized.

Objectives: The aim of this session is to explore relational ethics as a way to approach equity in public health palliative care in order to support clients facing structural vulnerabilities.

Design/Methods: Case based discussions theoretically-informed by relational ethics will be used to show how a relational ethics framework can facilitate the development of collaborative partnerships with clients, health care providers, and community-based stakeholders to enable an equity and public health focused approach to the delivery of palliative care.

Results: In this session, learners will explore how relational approaches can support decision-making and care delivery that is trauma-informed, harm reduction focused, culturally sensitive, and supportive of clients' values.

Conclusion: Relational ethics can support social change in equity and palliative care by contributing ethically-informed ways of caring for/with/about individuals who are highly marginalized.

ID: 161
Abstract Type: Poster

Topics: Relationships and connection, Educational approaches

Keywords: chronic diseases, quality of life, private/public collaboration, health education, social connection

Promoting a shared approach to improve health in chronic disease: a proposal of a private/public joint program

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Background: Emilia-Romagna region in Italy promotes and supports, through the program called "2023 Social Innovation", private organisations and institutions who have projects involving satisfaction of social and health needs, also through the activation of new relationships, referring to certain communities of people/users/groups of individuals and/or to certain territories.

Objectives: Description of the project "Collaboration and prevention together : an innovative model of health", a proposal of joint-venture between private rehabilitation center and publich healthcare system for person-centered care program for patients with chronic diseas as cancer, cardiovascular diseaes, diabetes and neurological diseases.

Design: A rehabilitation medicine center in Ravenna, with the support of Emilia-Romagna region, will promote shared care pathways for people with chronic diseases as stated before, in order to implement personalized care pathways to improve both outcomes of quality of life and social connection

Methods: Patients coming from public health system facilities will have multi-professional evaluation: cardiology and rehabilitation medicine physician together with physioterapists with a degree in physical education and sport sciences will develop personalized goals and shared outcomes of care for the patient.

Results: "Collaboration and prevention together" program hopefully will achieve a virtuous cycle where patients with chronic diseases will have the opportunity to improve their health and quality of life, in a productive collaboration among Healthcare professionals, institutions and citizens.

Conclusions: Shared programs between public institutions and private healthcare organizations to promote public health outcomes in chronic diseases could be an innovative way not only to enhance quality of life of patients, but also to promote social connections and health education.

ID: 162
Abstract Type: Poster

Topics: Networks and compassionate communities, Care in humanitarian contexts

Keywords: accessibility, community, good death, palliative care

A gap in palliative care provision in communities in regional health 12, Thailand

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Palliative care development in Thailand was classified into the 4a level while it has been ranked 36th of 81 countries on Expert Assessments of the Quality of Death and Dying. Community-based palliative care is recommended to improve the accessibility of palliative care provision. The objectives of this research were to describe the current palliative care provisions that were implemented and to identify gaps by comparing them with evidence-based best practices recommendations.

Design: Case Studies

Method: Research settings included 4 provinces in Regional Health 12. Participants were stakeholders involved in palliative care. The total number of informants is 252 persons. In-depth interviews, participant observation, and group discussions were used to gather data. 213 patients and caregivers who received palliative care services were asked to complete the self-perceived quality of palliative and end-of-life care questionnaire. Data were analyzed using content analysis and descriptive statistics.

Results: Current practices to promote good living and good dying through palliative care services in the community can be classified into hospital-based palliative care and integrated community-based palliative care. The perceived quality of palliative and end-of-life care in the patient sample was at a high level in all aspects, except in care during the dying phase, which was at a moderate level. Meanwhile, the caregiver samples were at a high level in all aspects, except for bereavement care, which was at a moderate level. The results of the gap analysis include affordability of care, availability of medicines and medical equipment and supplies, palliative care education and training, human resources and, community participation.

Conclusion: Findings from the study highlight the strengths of the leadership and health service network team in the palliative care operations of Health Region 12. However, there are areas for improvement and challenges. Recommendations for promoting good living and good dying in communities will be addressed.

No Conflict of Interest

National Health Commission Office granted research funding.

ID: 163
Abstract Type: Poster

Topics: Policy and advocacy

Keywords: COVID-19 infection, opioid, benzodiazepine, specialist palliative care, generalist palliative care

Quantifying Clinical Load and Role for Generalist Palliative Care during the COVID-19 Pandemic - results from a cohort study on the Predictors of High Opioid and Benzodiazepine use In COVID-19 patients (PHOBIC)

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Background: Dyspnea is the most common symptom in COVID-19 patients, particularly in the terminal phase. It is difficult to manage because it rapidly worsens as the patient deteriorates within days of illness onset. In addition to severe physical symptoms, physical isolation and survival uncertainty aggravates the patient's anxiety and depression. This forms the impetus of palliative care's role in symptom control and facilitating goals of care discussion to address physical, psycho-emotional, social, and spiritual needs. However, since Specialist Palliative Care (SPC) may not be available widely, there is a need to quantify and profile a group of severe COVID-19 patients with low opioid usage who can be supported by Generalist Palliative Care (GPC).

Objectives: To measure the quantity and identify clinical factors of patients with severe COVID-19 infection who can be supported by GPC.

Design/Methods: This retrospective cohort study examined non-ventilated severe COVID-19 patients admitted to the National Centre for Infectious Diseases (NCID) in Singapore and seen by SPC from January 2021 to July 2022. Patients were either directly referred (DR) to SPC or screened by an SPC Advanced Practice Nurse using the early identification (EI) criteria based on resuscitation status and oxygen requirement. Baseline demographics were collected. Clinical status based on the International Severe Acute Respiratory and emerging Infections Consortium (ISARIC-4C) score, Edmonton Symptom Assessment System revised (ESAS-r) and palliative-related treatments were recorded. Patients with a morphine equivalent daily dose (MEDD) of $\geqslant$45mg and/or benzodiazepine use for dyspnea were grouped as high users, while patients with MEDD $<$45mg were considered as low users. We conducted multivariate analysis to identify factors in patients suitable for GPC.

Results: 234 patients were included. 109 (47%) tested positive through EI with a median

ISARIC-4C score of 14 (IQR 12-16). Amongst the EI patients, 51 (67%) needed opioid infusion, and only 45 (41.3%) were high users. Amongst the DR patients, 73 (58.4%) received opioid infusion, and only 50 (40%) were high users. A multivariate analysis indicated that patients with low ESAS-r graded dyspnea scores and respiratory rates were low users.

Conclusions: 60% of patients with severe COVID-19 infection were low users and can be supported by GPC. Further studies should quantify role of GPC in other life-limiting illnesses.

Conflict of Interest/Funding: None.

ID: 164

Abstract Type: Oral presentation

Topics: Research methods, Care in humanitarian contexts

Keywords: Chronic Pain, Pain Management, Eastern Africa, Culturally Sensitive Care

Chronic pain among Somali pastoralists in Ethiopia: A mixed-methods study

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Background: Despite chronic pain being one of the leading causes of disability worldwide, it lacks the necessary prioritization in global health agendas. Pain management as an essential component of palliative care remains particularly neglected in the global South and among marginalized communities, such as pastoralists, with underrepresentation in Sub-Saharan Africa's pain research.

Objectives: To explore the perceptions, notions and burden of chronic pain among adult pastoralists in the Somali Regional State of Ethiopia.

Design: The study followed a mixed-methods sequential exploratory study design. The project is embedded within the Jigjiga University One Health Initiative (JOHI). The initiative strives to improve the health and wellbeing of pastoralists, using transdisciplinary research approaches.

Methods: In the qualitative study phase, focus group discussions and semi-structured interviews were conducted with health professionals and pastoralists. The insights from the studies formed the foundation for developing a pastoralist-specific questionnaire to assess chronic pain burden. The questionnaire was piloted and later applied in a survey among 150 households. The households were randomly selected using GPS-based household location.

Results: Chronic pain was perceived as a complex, interconnected experience, with no specific term for pain in the local language. Pastoralists relied on distinct illness beliefs, where spirituality and community played a mediating role. Stigmatization and stoicism hindered pain reporting, with health professionals exhibiting demeaning attitudes. The survey indicated a chronic pain prevalence of nearly 30% among adult Somali pastoralists, with women and the elderly being more vulnerable. The body sites most commonly affected were the knees, followed by the lower back with moderate interference on overall activity and enjoyment.

Conclusion: This study reveals a substantial burden of chronic pain likely impacting not only pastoralists themselves but also their livelihoods, animals, and communities. The findings provide an in-depth understanding of chronic pain in a unique context, emphasizing the importance of culturally sensitive, pastoralist-specific pain management. Aligned with global health agendas, the study advocates for equitable access to comprehensive health services for vulnerable populations. Recognizing and incorporating pastoralists' self-care practices and lay health knowledge into the palliation of pain is essential.

ID: 165

Abstract Type: Oral presentation

Topics: Death and grief literacy, Artistic and creative approaches

Keywords: Death taboo, Death litteracy, Palliative care, Art-based methodologies

Challenging taboos surrounding palliative care through theater: a participatory research-creation

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1) Idea: Day after day, many terminally ill patients pass away without having had access to

the care they would have needed. This is partly due to a lack of knowledge, apprehensions, misunderstandings, myths, and taboos surrounding palliative care among the general public, patients themselves, their close ones, and some healthcare professionals. Faced with this realization, it appeared necessary to create new ways of raising awareness and educating the general public and healthcare professionals who are not specialized in the palliative care approach. Thus was born the idea of a collaborative documentary theater project, focusing on the transition to palliative care, and serving as a starting point for a citizen conversation on the topic. 2) Achievements: Through the implementation of a rigorous participatory research-creation process, combining qualitative and art-based research methods, our transdisciplinary team co-created a sensitive, truthful, and educative play on palliative care. The fictional work was constructed and validated using the perspectives of patients, their close ones, and palliative care professionals, as well as during public readings. The final play was presented 15 times in the format of a video recording, followed by discussions with the audience. Furthermore, the play has been presented in an academic context to students in medicine, psychology, social work, nursing science, and bioethics. Pre-post descriptive and qualitative data on the understanding of palliative care, among other things, were collected after each presentation of the work. 3) Conclusion/Lessons learned: The collected data show that watching the play could contribute to a better understanding of palliative care among the general public and healthcare professionals who not specialized in the palliative care approach. The results further suggest that theater could be a relevant cultural mediation modality to demystify palliative care and dispel certain associated taboos. Nonetheless, certain challenges remain regarding the broad dissemination of the work, particularly in reaching marginalized populations.

ID: 166
Abstract Type: Workshop

Topics: Death and grief literacy, Technology and digital innovations

Keywords: MAiD, Assisted Dying, death literacy, digital stories, podcast, education

Disrupting Death; Engaging in community conversations about Medical Assistance in Dying (MAiD)

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Background: On June 17, 2016 the Supreme Court of Canada passed a law permitting Medical Assistance in Dying (MAiD) following the landmark case of Carter vs Canada. Now that established mechanisms for the provision of MAiD are available, it is important to understand what information and supports people need during the time before the assisted death occurs. It is integral that we develop insight into the impact MAiD has on Canadians to better understand the ramifications of the changing landscape of end-of-life care. There is a shift happening now as many Canadians are beginning to appreciate the need to have conversations about what is important to them at the end of life and take action which allow them greater control over their dying experience. Death is being disrupted and is no longer viewed solely as a medical failure but rather as a normative life event. This important life experience is one that Canadians are keen to reclaim and play an active role in shaping the healthcare systems and policies that frame it. This workshop project will provide insight into experiences in Canada and the efforts making to improve education and social discourse on MAiD.

Target Audience: People who are interested in learning more about MAiD in Canada and some of the community engagement efforts being used as part of a national research study exploring Canadian experiences with MAiD.

Learning Objectives: 1). Acquire a deeper understanding of the experiences of Canadians who are intimately impacted by MAiD throught the sharing of digital stories 2). Increase understanding of the experience of Canadians who have supported someone who chose MAiD at the end of their life through digital stories, a podcast and community education initiatives.

Structure of the Workshop: This experiential workshop will share some of the integrated knowledge translation tools informing a 5 year national research project on Canadians experiences with MAiD. It will begin with a short background on the history of MAiD in Canada, the context and the present day landscape. The workshop will focus sharing 3 different community engagement initiatives utilized in the research project as ongoing tools for knowledge translation. 1). Digital stories created by people who have experiences with MAiD. 2). An overview of the reach and lessons learned from launching a podcast “Disrupting Death” in Feb. 2023. 3). “Die-alogues” community engagement event hosted by the research team.

ID: 167
Abstract Type: Oral presentation

Topics: Research methods

Keywords: mixed-methods, under-served communities, public health, palliative care

Improving access to and delivery of palliative care for underserved populations: a 5-year research program

Jaklin Ardath Eliott[1], Gillian Harvey[2], Kate Gunn[3], Anna Chur-Hansen[1], Gregory Crawford[1], Caroline Laurence[1], Clemence Due[1], Ann Dadich[4], Lucie Walters[1], Ali Lakhani[5], Timothy To[6], Linda Foreman[7]

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Background: Palliative care (PC) is not equally available to all Australians, due to geography, economics, workforce, awareness, and accessibility. There are known groups and communities who do not typically access PC services, including within rural, low-socio-economic, and culturally and linguistically diverse communities. With an ageing population, these disparities are forecast to increase.

Objectives: This 5-year research program (2022-2027) addresses deficits in accessing PC for such under-served communities, whilst strengthening what works well.

Design: Taking a public health perspective underpinned by theories of knowledge translation, co-design, and community engagement, we address micro, meso, and macro elements impacting the delivery and receipt of PC.

Methods: Our program includes 1. a 3-year longitudinal study following patients and families in the last year of life to identify PC needs and priorities within under-served communities, capturing real-time, lived experiences of those facing death and bereavement. Within communities and residential aged care facilities, we will identify the precursors to, triggers for, and consequences of those decision-points that see a change in care needs; 2. Supporting community leaders to share information about death, dying, and PC within their communities according to their priorities and preferences, measuring death literacy before and after a program of activities (all materials presented in preferred language); 3. a cross-sectional case-note audit of, and survey patients within urban and rural public hospitals, aged 55+ years with deteriorating health and increasing care needs, to document unmet needs and engagement with PC, with follow-up 12 months later to capture admission and mortality outcomes and variation according to sociodemographic and disease-related factors; 4. model the health workforce required to deliver PC meeting the needs of under-served populations; 5. a national discrete choice experiment to identify the optimal combination and relative of importance of characteristics affecting PC decisions, and differences when responding as patient or carer.

Results: This presentation is an overview and report on project aims, activities, and outcomes to date.

Conclusion: Through processes of engagement and relationship building with/within community, industry, academia, and government, our comprehensive program enables relevant, feasible, translatable, and sustainable change in PC access and delivery.

ID: 168
Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: hospice movement, compassionate communities, migration, networks, volunteers

At the End Diversity. A project to integrate volunteers with migration background into activities of a hospice movement in Germany

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Hospizgruppe Freiburg e.V., Germany

Background: In 1991 a Hospice Movement was founded as a charity in a German University City. The aim of this charity is to promote the hospice movement in the public. With the support of volunteers it helps to accompany very sick and dying people and to support families in their care and bereavement.

Over the years different projects and changes to services (individual counselling, walking group, dancing group, gatherings at death cafes, discussion group for young widowed women and men, etc.) have been developed. Co-operations with different institutions and services have been built. A special service has been established to support grieving children, adolescents and young adults.

Objectives: The obligations of a hospice movement are to accompany all people in their dying and bereavement. A new challenge is how to include our migrant population as society rapidly changes. The existing volunteers need to be trained about diversity and discrimination. A further step is to involve those who have a migration experience themselves as volunteers.

Design: This project 'At the End Diversity' financed since 2022, helps to support diversity in the hospice movement. It aims to establish a network of care and accompaniment for people by volunteers including those with migration experience. This results in establishing connections between all involved to facilitate more access to hospice care.

Methods: To evaluate how people with migration experience can participate as volunteers and engage in the hospice movement to enhance diversity.

Results: Advice centres, neighbourhood offices, language mediation centres, migrant self-organizations and hospice/palliative care services have been established.

This requires openness to face an unfamiliar reality. This open mind approach of care helps to meet the new and greater needs of our more diverse everchanging society. It needs flexibility of all people involved. It enhances resilience and seeks to discover underused or not all used human resources.

Conclusion: It is a challenging experience to gain insight how suffering is integrated, faced and responded to by migrant people with different ethnic, linguistic and spiritual cultures. If it is respectfully done in an openminded non-judgemental way, it enriches all involved in the hospice movement. If this project is successful it will be established as a new regular hospice service.

ID: 169
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving

Keywords: palliative care, burden of disease, health service planning, needs assessment, underserved populations

Concerns and care needs of older patients in South Australian urban and rural public hospitals

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Background: Australia has an aging population. Of approximately 160,000 deaths annually, 82% occur in people aged ⩾65 years. In the last year of life, South Australians have many hospital admissions. Most die there, often having costly, difficult medical treatments that do not improve their lives. Palliative care can reduce admissions, interventions, costs, and improve quality of living and dying for patients and families facing life-threatening illnesses. However, despite inequities in access to high-quality palliative care (e.g., rural, disadvantaged, or from non-English speaking backgrounds), we know little about what healthcare these groups of people need or get as they approach death, and whether this differs from mainstream, dominant populations.

Objectives: To identify a) the unmet needs and care received for acute care populations ⩾55 years in South Australia assessed as being in, or close to, the last 12 months of life; b) differences in needs and care according to sociodemographic and disease-related factors.

Design: Cross-sectional case-note audit/survey.

Methods: Data were collected via an online portal in March-June 2024, within 6 urban and 4 rural public hospitals over 2 consecutive days each. With consent we audited hospital case-notes for the preceding 12-months for in-patients aged ⩾55 years. For those identified with deteriorating health and increasing healthcare needs, we documented why they attended hospital, treatment limitations, number of admissions, and any medication review. Using a modified Distress Thermometer, we surveyed participants about their current psychosocial concerns, level of distress, unmet needs, and their awareness of palliative care services. We will review records in 12 months to determine subsequent hospital admissions and mortality status.

Results: We report on 1. the current care, treatment limitations, and hospital admissions; 2. distress levels, psychosocial concerns, unmet need, and awareness of palliative care; and, 3. variation associated with socio-demographic, geographic, or clinical (excluding mortality) factors.

Conclusion: We present preliminary recommendations for healthcare clinicians, managers, and policy-makers about participant needs and concerns, and, by identifying variation across population groups, facilitate future planning for the healthcare workforce needed to meet the needs of an aging population and deliver care people want and need, regardless of diagnosis, who they are, and where they live.

ID: 170
Abstract Type: Poster

Topics: Relationships and connection, Death and grief literacy

Keywords: death literacy, under-served populations, mixed methods, community engagement, ethnic minorities

Working with communities: Helping you to live well as long as you can (promoting death literacy in ethnic minority communities)

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Background: Under-served and under-studied population groups disproportionately affected by social inequalities do not habitually access palliative care services. This suggests that those in these groups do not have access to palliative information and services that meet their needs, contributing to and reflecting low levels of health and death literacy (i.e., the language, knowledge, and practical skills needed to make active end-of-life choices).

Objectives: To evaluate a) if working with community leaders with four targeted culturally and linguistically diverse (ethnic minority) communities to design and deliver materials via culturally appropriate, accessible language and modes of delivery is associated with an increase in death literacy within their communities; and, b) the experiences and observations of community leaders regarding their involvement and study processes/outcomes.

Design: Mixed methods: quantitative—pre-post evaluation, qualitative—focus groups.

Methods: Collaborating with local peak-bodies advocating for palliative care and minority ethnic communities, we provided training and support for community leaders within four language-groups/communities (i.e., German, Italian, Tagalog (Filipino), and Vietnamese) to undertake various activities sharing information about death, dying, and grief within their community.

Results: We report on the processes and outcomes of this study specifically regarding a) a pre-post (at 0 and 6m) intervention study, to quantitatively assess the effectiveness of community-led activities in promoting discussion and knowledge regarding death, dying, and palliative care, accounting for local conditions and cultural factors; and b) focus groups during and after the intervention, drawing on community leader views on the process and outcomes of their engagement with researchers, palliative care advocates, and other community leaders; their community-based activities' the processes of translation for consent and administration of the Death Literacy Index within their community; and the nature of activities undertaken to capture and strengthen community resources regarding accessing and providing care for those at the end of life.

Conclusion: We highlight the differences and similarities within communities and outline provisional recommendations for future collaborative engagement with other under-served populations regarding discussions about, promotion of, and conduct of research about death literacy.

ID: 171
Abstract Type: Poster

Topics: Relationships and connection, Social and structural determinants of death dying and grieving

Keywords: end-of-life, mixed-methods, longitudinal, under-served communities, families

My Story, Our Journeys: the experiences of patients and families in the last year of life

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Background: In many developed nations, an ageing population, patterns of health trajectories, and accessible options for end-of-life care influence what is possible for what and where palliative care is provided. Experiences of and preferences for giving and receiving care can differ markedly and are impacted by cultural and familial beliefs and expectations, and unexpected ramifications of illness (e.g., symptom management, length/intensity of care requirements, and financial costs).

Objectives: To document how, why, and what decisions a dying person and their carers make about how, where, and what care is provided in the last year of life; and, identify the precursors to, moments of, and consequences of (changing) decisions regarding care.

Design: Prospective 3-year longitudinal mixed-methods (data collected at 12-weeks intervals) study with a cohort of people living with a life-limiting illness and declining health, and their carers (typically family) from communities known to have limited access to palliative care—rural, low socio-economic, or non-English-speaking origin communities.

Methods: We have begun recruitment and engagement with 40-64 patient-carer units, within communities, residential aged care facilities, and acute care settings. Quantitative analysis will use a multilevel modelling approach to identify variation in factors (e.g., location, ethnicity, gender, psychosocial status) associated with change within and between patient-carer units in self-report surveys (measuring performance status, care needs, quality of life, psychosocial wellbeing). Qualitative data (e.g., interviews, videos, photos, pictures) will be thematically analysed within a pragmatist orientation, focusing on implications for clinical practice and policy for end-of-life and bereavement care.

Results: We present preliminary findings about the last year of life and into bereavement on a) behaviours, experiences, and key moments, shaping how and why people from under-served communities make decisions about care; and b) changes over time in expectations and experiences, challenges and benefits, needs, expected futures and factors associated with a change in experience and/or expectations of providing or receiving care.

Conclusion: We present preliminary observations and recommendations to inform the development of resources to ensure timely provision of information to, and support for, patients, families, and carers negotiating and living with decisions about care at the end of life.

ID: 172

Abstract Type: Poster

Topics: Educational approaches

Keywords: education, end-of-life, nursing home, course

Impact of an ‘End-of-Life Education’ Training Course on Knowledge and Attitudes of Nurses and Patient Care Assistants in a Nursing Home

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Background: Many individuals opt for nursing homes as their preferred place of care and death. However, nursing home staff face significant challenges in providing end-of-life (EOL) care; contributing to these difficulties are a lack of knowledge and confidence in end-of-life care. We postulate that a targeted education course to nursing home staff may help to overcome the gaps.

Objectives: To improve knowledge of EOL care and change attitudes of nurses and patient care assistants (PCAs) at a nursing home through an educational intervention.

Design: The intervention consisted of small-group teaching focused on end-of-life care within an institutional setting. It included six hours of teaching over three sessions. A multi-modal approach was used, including videos, case scenarios, didactic lectures, small group discussions, and hands-on exercises.

Methods: Before the course, a questionnaire was administered, which gathered demographic information, asked participants to rate their confidence, and tested their knowledge on EOL care. The same questionnaire was administered within a week after the course.

Results: Twenty-one nurses and PCAs attended the education course. There was an improvement in both knowledge and confidence in EOL care after attending the course. The greatest improvement was observed in PCAs and newer healthcare professionals. Correlation analysis did not find significant correlation between knowledge change and confidence.

Conclusion: The study demonstrated that an educational course effectively improves knowledge and confidence in end-of-life care among nursing home staff, with the most notable gains in PCAs and less experienced providers. However, the lack of significant correlation between knowledge and confidence suggests additional factors might influence care confidence. Future education could consider incorporating practice segments, such as bedside tutorials. This potentially bridges the gap between knowledge and actual care practices, and addresses individual learning needs of nursing home staff at different levels of experience. Ultimately, a customised and comprehensive educational program is essential to elevate the quality of end-of-life care.

ID: 173

Abstract Type: Poster

Topics: Death and grief literacy

Keywords: Dyspnea, Opioids, Morphine, Aids, palliative

Oral Morphine for Relief of Dyspnea in Chronically ill Patients at the End of Life: De-mystifying Morphine Use in sub-Saharan Africa

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Background: Dyspnea represents a very frequent and distressing symptom in patients on end-of-life care[1]. While opioids are the first line therapy for symptomatic relief of dyspnea, mysths surrounding morphine use continue to undermine it's use in sub-Saharan Africa.

Objectives: The main aim of this study was to ascertain the efficacy of oral morphine in relieving dyspnea in patients on end-of-life care.

Design: This was a randomly controlled, double blind study of 40 severely dyspneic patients with relatively well controlled underlying AIDS related comorbidities.

Methods: This was a double-blind, randomised, controlled cross over study to determine the efficacy of oral morphine in relieving the sensation of breathlessness in chronically ill patients whose underlying aetiology has been sufficiently treated.

Results: Of the 40 participants, 35 completed the study. Of these, the majority (95%) reported a significant improvement in their dyspnea.

Conclusion: Oral morphine at low dosage provides significant symptomatic relief in refractory dyspnea [2] in chronically ill patients on end-of-life in a community palliative care setting in sub Saharan Africa.

ID: 174

Abstract Type: Poster

Topics: Relationships and connection, Educational approaches

Keywords: Trust, physicians, communication, end of life, doctor-patient relationship, intervention study

Trust in physicians to provide good end-of-life care: before, directly after, and 6 months after an information meeting on end-of-life care

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Background: Research suggests that trust in physicians is a prerequisite for engagement in advance care planning (ACP). A pilot study demonstrated that information meetings on end-of-life care by general practitioners (GPs) increase trust in physicians and stimulate ACP among older people. However, it is unknown whether this is true for meetings held by other organizations (e.g. hospice).

Objectives: To examine whether patient's trust in physicians to provide good end-of-life care changes directly after and 6 months after an information meeting on end-of-life care, and whether this differs between meetings held by GPs or others.

Design: A pre-post interventional study was designed with questionnaires before (T0), at the end (T1), and 6 months after (T2) the information meeting. Between February 2021 and December 2022, 105 information meetings were organized, of which 57 by GPs and 48 by other organizations.

Methods: 1,737 older people filled out questions on trust at T0 and T1 and 1,083 at T0 and T2. Per type of meeting, separate marginal homogeneity tests were done to assess change in trust. Logistic regression analyses (Generalized Estimating Equations) were done to assess whether the type of meeting was associated with an increase in trust (corrected for age and sex).

Results: At T0, most attendees of GP and other meetings had high (resp. 55% vs 58%) or very high (35% vs 19%) trust in physicians to provide good end-of-life care. Attendees of GP meetings changed significantly in trust between T0 and T1 ($p<0.001$). Change in trust was not significant between T0 and T2 ($p=0.151$). Attendees of other meetings did not change in trust at T1 ($p=0.178$) nor T2 ($p=0.112$) compared to T0. Looking at direction of change, attendees of GP meetings were more likely to increase in trust (OR 1.74 CI 1.27-3.39) between T0 and T1 compared attendees of other meetings. There was no difference between GP and other meetings in increase in trust between T0 and T2 (OR 0.97 CI 0.64-1.46).

Conclusion: Overall, patient's trust in physicians to provide good end-of-life care was high. Information meetings by GPs resulted in a significant increase in trust directly after the meeting. This was not true for attendees of other meetings. Thus, having a physician present at the meeting may contribute to patient's trust, and possibly more engagement in ACP. The change in trust did not last after 6 months. Further research could provide insight in whether this differs for having had ACP conversations with GPs.

ID: 176
Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: caring community, palliative care, co-construction, public health

InVita! Pathways and actions for the creation of Caring Communities: discover, asses, focus, and commit

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Background: A medical management of death is becoming increasingly widespread, due to several emerging factors. Furthermore, the Covid pandemic has brought about a reduced focus on a bio-psycho-social approach to death. The essential role of the Community has been decreasing, while current Palliative Care Services cannot address all the needs brought by sick people and their relatives due to the high prevalence of patients with palliative care needs.

Compassionate communities/'caring communities' (C.C) have been proposed as a Public Health response to the management of serious illness, death, dying, and bereavement.

In this project we describe the Mapping phase (discover, asses, focus, and commit) of a project called "InVita!".

Objectives:

1. To identify the needs and resources of involved stakeholders, families, citizens
2. Identify potential beneficiaries and components of future intervention.

Design: Prospective observational study

Methods: Needs, resources, and interventions related to the end of life have been mapped. Community stakeholders were involved to actively participate in the co-design of the project. Twenty-two semi-structured interviews with InVita! stakeholders (healthcare and social services, voluntary and cultural associations) were conducted; three Focus groups with caregivers of deceased persons were developed together with participants and they will be co-conducted.

A survey of local citizens belonging to the local context will be carried out. NVivo software was used for qualitative thematic analysis. Triangulation of the data will be realized from the different types of resources.

Results: Eight themes arose from the interviews' analysis: 1) Needs and Challenges; 2) Resources 3) Facilitators to the realization of C.C.; 4) Projects relating to end of life in the past; 5) The stories/description of the associative realities; 6) Potential actors to be involved; 7) Expectations; 8) Motivations to participate in InVIta!

The data from focus groups and survey will be triangulated with the interviews to identify further themes.

Conclusions: The data collected from this study will allow to identify intervention/interventions for the design and implementation of a sustained C.C.

Funding: The project was partially funded by MANODORI Foundation and Azienda USL-IRCCS Reggio Emilia.

ID: 177
Abstract Type: Poster

Topics: Research methods

Keywords: home healthcare, palliative care, knowledge, attitudes, survey research

Palliative care-related knowledge, attitudes & confidence in home health care: Results from a U.S. pilot study

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Background: In the United States (U.S.), the rising use of home health care (HHC) services among people with multiple chronic conditions highlights a need for home-based palliative care (PC). However, only 7% of such programs in the U.S. are operated by HHC agencies. Integrating PC into the HHC setting could improve patient outcomes. Prior to integration, better understanding of clinician readiness for and patient/caregiver receptiveness of PC are needed.

Objectives: Develop 2 questionnaires to assess readiness for and receptiveness of PC among U.S. HHC clinicians' and patients/caregivers, focusing on knowledge, attitudes, and confidence (KAC).

Design: A cross-sectional pilot study guided by the 2018 National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care.

Methods: We adapted existing PC-related KAC scales and added new items to cover all eight NCP Guideline domains. Following expert review and 20 cognitive interviews, we refined the questionnaires. The final versions have 3 sections assessing KAC with 56 items for patients/caregivers and 95 for clinicians, including core and role-specific items. After IRB approval, pilot testing was conducted at a large, urban U.S. HHC agency. Descriptive statistics were calculated using Stata 17.

Results: 28 patients/caregivers and 30 clinicians (nurses, physical therapists, social workers) participated. Overall, 48.4% of patients/caregivers were unaware of PC. However, 31.3% of caregivers indicated they had some knowledge. Among patients/caregivers, knowledge gaps existed regarding pain management/opioid use, spiritual/cultural aspects of PC, and end-of-life (EOL) decision-making. Attitudes on pain management/opioid use varied. Caregivers were less confident in managing difficulty breathing and agitation, engaging in EOL discussions or providing EOL care. But 93.6% would consider PC for themselves or a loved one.

Overall, clinicians demonstrated adequate knowledge; however, several questions about pain management/opioid use and ethical/legal aspects of PC were answered incorrectly by >40% of clinicians. Clinicians held positive attitudes towards PC but had varying levels of confidence in PC provision.

Conclusion: We developed 2 PC-related KAC questionnaires for the U.S. HHC setting, laying the groundwork for PC integration. Broader questionnaire distribution will identify training needs and findings will enable tailored interventions for HHC patients, caregivers and clinicians.

ID: 178
Abstract Type: Workshop

Topics: Death and grief literacy, Artistic and creative approaches

Keywords: creativity, death anxiety, death literacy

Away from words: Using art-making to alleviate death anxiety in the palliative care workforce

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Target Audience: Our research into equity-oriented, arts-based approaches to advance care planning particularly for people from marginalized communities has led to the development of a facilitator training programme and to date over 200 people have been trained to use the approach in their communities. One of the unexpected findings from the facilitator training has been the resistance amongst the palliative care workforce to thinking about their own wishes for end-of-life care. Death anxiety has been shown to be more prevalent amongst the people working with dying people. There are multi-faceted reasons for this – self-protection, dying becoming 'business as usual', and 'them and us' thinking. The target audience for this workshop is the wider conference community, many of whom have worked for a long time in this field. Less verbal methods, such as art-making, are a useful way to connect with feelings and break down personal resistance. Engagement in conversations about death and dying and personal mortality have been shown to alleviate death anxiety and compassion fatigue in the workforce.

Learning Objectives:

- Space and permission to experience engagement in self-inquiry regarding death, dying and mortality
- First-hand experience of using less verbal, arts-based methods as a tool for reflection, learning and facilitation
- Engaging together creatively as a collective conference community in conversations and visual inquiry to promote death literacy
- Collective art-making – the creation of a collective art installation to be displayed during the conference

Structure of the Workshop

Introduction to background of method 15 minutes approximately
Themed art-making in response to structured questions 45 minutes
Group reflection following less verbal self-inquiry 30 minutes
Output: A collective artwork for and by the conference community
Note: Participants do not have to be good at art to participate. Participation in the collective art installation is voluntary.

ID: 179
Abstract Type: Oral presentation

Topics: Relationships and connection

Keywords: Social wellbeing, social isolation, advanced illness, adults

"Sorry to make you think my life is a misery but I am content": Experiences and Perceptions of Social Wellbeing among Adults Living with Advanced Illness

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Background: As global life expectancy rises, an increasing number of individuals living with advanced illnesses face prolonged periods of health decline, which profoundly affects their physical, social, emotional, and spiritual wellbeing.

Objectives: We sought to explore experiences and perceptions of social wellbeing, focusing on social connectedness and identity, among adults living with advanced illness and their informal carers in North-East England, UK.

Design and Methods: A qualitative study, with data collected through individual and/or joint in-depth interviews including a follow up interview and using adapted grounded theory approach to analysis.

Results: Nineteen adults living with advanced illness and 15 informal carers were interviewed. Due to the limitations imposed by advanced illness and life changes like bereavement, relocation, and retirement, all participants had over time experienced significant reductions in their social networks and activities. Their social relations changed from heterogeneous networks to smaller, close-family-only circles. A few participants maintained connections with friends and social groups. Nevertheless, many participants upheld a sense of belonging and meaningful existence through their interactions. These included the few close family and friends, 'familiar strangers and places', 'complete strangers', everyday activities, pets, and cherished objects from their past. This sense of belonging and meaningful existence changed constantly to accommodate

the constantly changing physical abilities and life situations.

Conclusions: Interventions to improve social wellbeing in advanced illness should be diverse and flexible, encompassing building social connections, strengthening existing connections, and a variety of meaningful activities. These may include maintaining simple daily routines, community access, and contact with valued places, people, and objects, and should be informed by context and individual elements like values, experiences, physical abilities, and personal preferences at various times.

ID: 180
Abstract Type: Oral presentation

Topics: Death and grief literacy, Educational approaches

Keywords: Assited dying, Education, Death literacy, Co-production

Co-developing community end of life choices education: Assessing and responding to death literacy and assisted dying learning needs

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Background: The Australian Capital Territory (ACT) has legislated to enable access to voluntary assisted dying (VAD) in 2025. In preparation, this multiphase project to explore community attitudes and learning needs relating to death literacy and VAD and develop resources to meet them began in late 2023. VAD attitudes are influenced by community members beliefs and emotions which may impact learning needs. Thus, to be effective education will need to address a variety of needs beyond knowledge alone. VAD is also only one type of end-of-life choice, and public education programs need to account for broader understandings of what is needed and valued at the end of life including death literacy. To ensure equity, appropriateness and access education will need to take account of the needs of underserved populations and be developed in partnership with the community.

Objectives: Phase one of this multi-phase project seeks to explore and document death literacy including VAD knowledge and attitudes, within the ACT community, including underserved populations e.g. those with socioeconomic deprivation, disabilities, first nations peoples or from culturally and linguistically diverse backgrounds, and those with advanced illness and/ or those caring for them.

Design: Triangulated mixed methods design using concurrent quantitative and qualitative methods.

Methods: After initial co-development, data was accrued from three populations of general residents, underserved populations and people with an advanced illness and their carers. Quantitative analysis of: the death literacy index (DLI) completed online by a representative sample of ACT residents and supplemented with purposive sampling of the other two target populations utilising descriptive statistics; a survey analysing a tripartite model of attitudes relating to VAD completed by the same populations utilising the generalised linear mixed model. Qualitative thematic analysis of verbal data from a purposive sample of participants from these three populations responding to discussion of death literacy and exploration of attitudes and needs relating to VAD and end of life care.

Results: Quantitative and qualitative results as described will be presented.

Conclusion: Introducing VAD provides an opportunity for communities to reevaluate their approach to end of life choices and to develop and renew the knowledge and resources they have available at the end of life.

ID: 182
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, The value of death

Keywords: Distress in cancer patients, Chemotherapy, cancer patients, distress thermometer, unpleasant experience

Determinants of distress among cancer patients admitted for the day care treatment at a tertiary care Cancer hospital, Amritsar, Punjab

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Introduction: Distress is very common in patients with cancer but it often goes unidentified. Sociodemographic, clinical, and psychosocial variables have been identified as major risk factors for distress and it extends along a continuum, ranging from common feelings of vulnerability, sadness, and alarming to problems that can become disabling.

Objectives: To determine the level of distress among cancer patients and sociodemographic factors affecting distress among the cancer patients.

Materials & Methods: The study was a cross sectional study using purposive sampling technique. All the patients above 18 years who were admitted from 1st March 2021 to 31st August 2021 were included in the study.The information was collected from patients using NCCN Distress Thermometer (DT) and problem checklist, a validated tool to assess the distress levels and their association of distress with problems. The data was compiled and statistically analysed using Statistical package for social sciences (SPSS Software 23.0 version) IBM Chicago.

Results: out of 567 participants, 64.6% study subjects were above 50 years. This shows that the number of patients were increasing with increasing age. In all, 60.5 % were females and 39.5% were males. Majority of patients were having moderate to severe distress (50.6%) followed by 37.9% who had mild stress and 11.5% had no stress.It was observed that education, occupation and socio-economic status were significantly associated with the level of distress while age, sex and marital status had no association.

Conclusion: Holistic approach in cancer treatment including psychological, spiritual and emotional evaluation and its solution for the same at appropriate time enhances the quality of life of the patients. It is recommended that all health care providers should address these as a part of their routine practice.

ID: 183
Abstract Type: Poster

Topics: Educational approaches

Keywords: older persons, cancer, volunteer program, survey study

EU-Navigate training prepares navigators in European countries to support older persons with cancer living at home

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Background: Navigation helps persons get connected to resources they may not know about or have difficulty accessing. Nav-CARE, a navigation program in Canada, has illustrated that navigators can have a positive impact on the well-being of older persons living at home with chronic illness. EU Navigate is a European adaptation of this navigation program, in which both professional and volunteer navigators support persons of older age (>70) who have cancer.

Aim: The aim of this study is to explore motivations for becoming EU navigators and to evaluate the level of preparedness navigators experience after having participated in the EU Navigate training.

Design: Navigators were trained across five key competencies: (1) addressing quality of life concerns, (2) advocating for clients and families, (3) facilitating community connections, (4) promoting active engagement, and (5) supporting using technology. The first navigator trainings have been conducted in Belgium, Ireland, Italy, the Netherlands, Poland and Portugal.

Methods: After completion of training, a survey was conducted about motivations for becoming navigators and preparedness for the role of navigator on the key competencies. Descriptive statistics were conducted.

Results: The survey was completed by 79 navigators in total from all six participating countries. Most often, people were motivated to become navigators because of a desire to help another (48.1%), a wish to develop personal and/or professional skills (16.5%), or because they found

the project interesting or important (15.2%). Overall, navigators indicated that they understood what was expected of them regarding each competency (87.0%-96.1%). Moreover, they reported to be confident in their ability to successfully execute each competency as navigators (75.6%-86.7%).

Conclusions: People who have participated in the adapted EU Navigate trainings feel prepared to start working as a navigator. The navigators' confidence in their role serves as a favorable foundation from which to start navigation.

Funding: EU HORIZON-HLTH-2021-DISEASE-04: 101057361 — EU NAVIGATE

ID: 184
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Educational approaches

Keywords: education, migration, sensibilisation, health professionals, communication

Raising awareness of migration issues in palliative care

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Concept: There are indications that certain population groups have limited access to palliative care due to individual or structural criteria (Swiss Federal Council, 2020). People with a migration background and additional burdens, such as a lack or low level of education, uncertain residence status and a lack of language skills, therefore find it more difficult to access palliative care services (Amstad, 2020).

To make matters worse, people with a different socio-cultural background often have different perceptions of dying and death. Adequate information and awareness are needed in future, to improve the quality of life for these people in the terminal phase of life.

Implementation

Materials have been developed to make professionals and volunteers in various outpatient and inpatient palliative care settings more aware of migration-specific issues and improve their transcultural skills.

Theoretical principles, exercises and other tools, such as checklists and questionnaires, have been developed or compiled based on the questions that arise in practice. The content has a modular structure so that the focus can be adapted to fit the individual. The exercises are used for introspection into one's own actions and can be worked on in groups or individually.

Module 1: Dealing with diversity – transcultural competence
Module 2: Transcultural communication in a palliative care setting
Module 3: Different perceptions of illness, dying and death
Module 4: Relatives and decision-making
Module 5: Spirituality, rituals, returning to the country of origin
The modules were tested in training sessions with the staff of a Spitex institution and a retirement and nursing home.

Conclusion: The training content serves to raise awareness of professionals and volunteers to migration-specific aspects of palliative care. The modules are suitable for a broad audience and a variety of professional groups. The content is available free of charge in German, French and Italian from October 2024 at www.migesplus.ch.

ID: 185 / 186
Abstract Type: Oral presentation

Topics: Death and grief literacy, Educational approaches

Keywords: death literacy, grief literacy, palliative care, Last Aid Course

LAUT: Last Aid at the workplace as a sensitive approach to death and grief

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Background: The number of deaths in Germany in 2023 was 1.02 million, of which around 50% are of working age. Statistically, everyone is likely to be confronted with the effects of death, bereavement and mourning at some point in their career. Dealing with death and bereavement can impact workplace well-being and productivity. However, individuals affected by the effects of death, bereavement and grief often lack necessary workplace accommodation, such as reduced working hours, and emotional support and compassion from employers and colleagues. Last-aid providers in the workplace serve as direct contacts and integrate conversations about death, dying and grief as a normal part of everyday working life. The aim of the LAUT project is to develop a framework of implementing last-aid provider workers at the workplace.

Methods: (1) In a representative online panel survey (Germany-wide), managers and employees (n=1000) will be asked about their experiences with dying, death and grief in the workplace. Needs for changes in dealing with dying, death and grief are recorded. (2) After the training of last-aid the content of the training will be evaluated with regard to its application in the workplace using questionnaires. (3) Focus group interviews with trained end-of-life caregivers will be used to gather ideas for the reorganisation of content and possible implementation of last-aid providers.

Results: The project will run from 01/10/2023 to 31/12/2025. Results are pending.

Discussion: Last-aid providers could relieve people in the workplace in dealing with dying, death and grief and thus make a contribution to social capital. They provide emotional and practical support, access to open dialogue about burden and grief and create spaces for mourning.

The results of this project can be used to develop important recommendations for action for companies and organisations. The implementation of last aid providers in the workplace can be a promising approach to sensitively support people in burdensome situations at work. The more employees and managers know about the theoretical background, the better they can provide appropriate support.

Practical implementation: It is important to investigate the long-term benefits of last-aid providers at the workplace. The implementation of last-aid providers can serve as a resource for increased well-being, an open communication culture and as motivation for developing guidelines for dealing with dying, death and grief in the workplace.

ID: 187
Abstract Type: Poster

Topics: Artistic and creative approaches

Keywords: Music, art, therapy, quality of life

Art and Music therapy in Patients' LIFe QualitY (AMPLIFY) - an interim analysis from a tertiary based palliative care service

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Background: Art Therapy (AT) and Music Therapy (MT) alleviate symptoms such as pain, anxiety and depression. However, there are limited studies demonstrating the benefits of AT and MT in patients receiving palliative care in acute tertiary hospitals.

Objectives: This study aims to assess the impact of AT and MT on the quality of life (QoL) of inpatients receiving palliative care in an acute tertiary hospital. The primary and secondary outcome of the study is AT and MT's effect on QoL and symptom burden respectively. The hypothesis is that AT and MT will improve McGill Quality of Life Questionnaire (MQoL-Q) scores by at least 2 points after 1-2 sessions of therapy.

Design: AMPLIFY is a mixed methods interventional observational study. Patients with any life-limiting illness with a prognosis of less than a year will be eligible to enrol in the study and participate in 2 sessions of AT or 2 sessions of MT.

Methods: The primary outcome is measured using the MQoL-Q, and symptom burden with the Edmonton Symptom Assessment System-revised (ESAS-r). Participants will complete the MQoL-Q and ESAS-r at 4 times points (T_0 toT_3). Baseline data will be collected prior to intervention (T_0), within 2 working days after each therapy session (T_1 and T_2) and 2 weeks from T_0 (T_3). Therapy sessions will be scheduled 2-7 working days apart from each other. Based on powered sample size calculations, we aim to recruit 280 participants. For the qualitative component of the study, semi-structured interviews will be conducted with participants 2 weeks after the second therapy session.

Results: This is an interim analysis of the ongoing study. Of 305 patients screened, 180 participants were recruited. 102 participants completed at least 1 therapy session: 35 died before study completion, with 25 participants too physically or emotionally unstable to complete the sessions and/or questionnaires. 11 were discharged before study completion and 7 withdrew. 98 participants completed the MQoL-Q at T_0 and T_3, and 57 participants (58.2%) showed an improvement of at least 2 points, the Minimal Clinically Important Difference (MCID) of MQoL-Q, between T_3 and T_0. 102 participants completed ESAS-r at T_0 and T_3, and 78 participants (73.6%) showed an improvement of at least 1 point, the MCID of ESAS-r between T_3 and T_0.

Conclusion: Our preliminary results demonstrate that AT and MT delivered alongside standard inpatient palliative care has a role in augmenting patients' QoL.

ID: 188
Abstract Type: Poster

Topics: Relationships and connection, Networks and compassionate communities

Keywords: community, grassroots, bereavement

A grassroots approach to Compassionate Communities

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Background: Brereton and Ravenhill is a village in Staffordshire. It has been recognised as a compassionate community for over two years, via Brereton Million (BM) (the organising group). During the COVID pandemic the community mobilised support from citizens in a variety of ways. This included residents sitting alongside people who were dying and another group of residents becoming 'phone buddies', often for people who were grieving, lonely and isolated.

Objectives: BM continue to have a busy community agenda including a wide range of activities to reduce loneliness and support families. One of its ongoing areas of activity focuses on public health palliative care. For 2023 there were two specific target areas, i) bereavement training for residents and ii) an event to support people 'getting their affairs in order'. A number of people who supported individuals during COVID have struggled with the impact of deaths in the village and therefore some capacity building in this area was determined as a key priority.

Design: Each year, BM plan activities that relate to their compassionate community status. The aim is to increase the knowledge, skills and confidence of citizens. The team designed a week long programme to raise awareness of activities such as wills, care plans, funeral planning etc and in addition ran some bereavement training for residents.

Methods: The week long event included a range of activities including an information session followed by a series of workshops, local market place of supporting organisations and opportunities to write wills. The bereavement training was designed to provide an insight into grief theory but mostly focused on building confidence around how to support others.

Results: The events were broadly successful, more people got involved over the week, particularly around the opportunity to write a will. Those who attended reported that they were now more aware of the range of formal and informal documents needed to support their advanced care and loved ones after they've died. The bereavement training also evaluated well, and a new bereavement support group has been established for the citizens of the village.

Conclusion: The week long event had the right mix of inputs, however promoting the event needs a new approach. For 2024 there will be a 'festival' to encourage higher attendance. The bereavement group whilst early days is progressing well and will hopefully support residents in this post COVID era.

ID: 189
Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: Compassionate communities, end of life care, community awareness and training

COMPASSIONATE CASCAIS Community project to promote the culture of compassionate care By Associação Oficina da Compaixão

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Background: Oficina da Compaixão - OC is a Portuguese, Non Profit Association, founded in 2021, which mission is to develop community care networks that, when sensitized, informed and trained, guarantee compassionate, collaborative, safe and effective care, in the physical, emotional, social and spiritual dimensions, for elderly people and/or with advanced chronic diseases and/or end-of-life condition - EPACDELC, and their families.

Objectives: Compassionate Cascais - CoCa, contributes to promote a culture of Compassionate Community - CoCo among community partners, focusing on Home Support Teams, Informal Caregivers and Volunteers who care for EPACDELC, in the territory of Cascais, 30 Kms from Lisbon.

Design: Cascais has only one community palliative care - PC support team to attend a population of 147.000 that have PC needs*. The players and decision-makers in the Municipality were consulted, to validate the relevance to invest in the area of end-of-life care, preparing the community to complete the available support. From there, priority groups were defined to 2023.

Methods: Based on the New Health Foundation's All With You Method, three axes were defined:

1. Awareness session for people over 65 years
2. Trainning program for home support teams, informal caregivers, and volunteers
3. Care Circles implementation

Results

1. CoCa developed 6 awareness sessions, attended by 145 people over 65, in community and day centers;
2. CoCa provided training sessions about the practice of compassionate care to 32% of the social entities working in home support, reaching 60 professionals and 20 volunteers. There was a significant improvement in knowledge and attitudes, evaluated through a pre/post questionnaire;
3. Where was an increase of people who makes part of the care circles in EPACDELC;
4. Achieving Level I Certification by NHF;
5. Host an event on the theme of CoCo, with 70 presences.

Conclusion: It's urgent to invest in the quality of support provided so that people live with the least possible suffering and quality of life until their last day. Mainly, because professionals in the social area do not have basic training in PC, there's an increasing necessity to invest in training. However, the cultural resistance to the issue of death, implies greater investment to achieve attitude changes and behaviors.

On the other hand, despite Cascais having innumerous resources to support EPACDELC, CaCo's intervention is essential to establish contact networks and access to them.

ID: 190
Abstract Type: Workshop

Topics: Relationships and connection, Networks and compassionate communities

Keywords: Death and Grief festivals, Community Engagement, Public Health initiatives

Fostering community engagement through Death and Grief Festivals: Insights from three case studies from Scotland, England, and Belgium

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Workshop Objective: A key aspect of a public health approach to palliative and end-of-life care is supporting communities to have conversations and learn more about death, dying, grief and bereavement, and reducing inequities in access to knowledge, information, and support. Festivals can help achieve these aims, offering different 'ways in' to these topics via participatory, creative, educational, and cultural events and activities. In this workshop, the organisers of three different festivals will share learning on different models of festivals and the challenges and opportunities inherent in their development and implementation. Qualitative and quantitative data on the reach and impact of these festivals will be presented. The objective is to encourage the audience to consider the utility of these approaches and exchange ideas for future endeavours aimed at enhancing community engagement with serious illness, death, and bereavement.

Target audience: The workshop is open to anyone interested in the development of festivals as part of a public health approach.

Structure of the workshop

1) **Getting to Know Each Other**
   - Who is in the room?
2) **Presentation of Three Case Studies:**
   - **To Absent Friends**, a Scotland-wide festival of storytelling and remembrance which has taken place annually since 2014. The festival aims to give people an excuse to remember, to tell stories, to celebrate and to reminisce about people we love who have died.

- **Good Grief Festival**, an online and in-person festival founded in 2020 which has now engaged over 30,000 people. The festival aims to engage people in research and scholarship related to grief, bereavement and end-of-life care, and to widen access to support and information.
- **The Compassionate Week**, held for the first time in November 2023, at Vrije Universiteit Brussel (VUB), Belgium, aimed to foster meaningful engagement among students and staff on profound subjects such as serious illness, death, and bereavement through various activities.

3) **Plenary Discussion:** Reflection on case studies – pitfalls, challenges, and opportunities.
   - How do we engage community members?
   - What other initiatives could be developed and implemented during a festival on this topic?
   - How can similar festivals be implemented in other countries, workplaces, educational institutions? What adaptations are necessary?
   - Experiences and questions from the audience
4) **Closing**
   - Summary of main lessons learned, where to go for more information and support

ID: 191
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Educational approaches

Keywords: Palliative care, end of life care, undergraduate education, medical and nursing students

Increasing access to primary palliative care through undergraduate education: New Zealand medical and nursing graduates' preparation, self-efficacy and attitudes towards providing palliative and end-of-life care

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[1]University of Otago, New Zealand; [2]Otago Polytechnic; [3]University of Auckland

Background: Advances in the management of life-limiting diseases coupled with an aging population mean there is an increasing prevalence of people with palliative and end-of-life care (PEOLC) needs in most healthcare settings around the world. Junior doctors and nurses are at the frontline of patient care, so it is essential they have the knowledge, skills and attitudes required to provide safe, effective, and compassionate care for people who are nearing the end of life. However, PEOLC has traditionally been under-represented in undergraduate medical and nursing education, which fails to prepare graduates for a core component of clinical practice and restricts access to primary palliative care for those who need it.

Objectives: This study aimed to investigate how medical and nursing students in New Zealand learn about PEOLC, their self-efficacy and attitudes towards caring for those with PEOLC needs and the factors that influence this process.

Design: Mixed methods doctoral research

Methods: Three-phase project with two national online surveys of education providers and graduates plus semi-structured interviews.

Results: PEOLC is under-represented in nursing education. Medical education offers more extensive learning opportunities and is guided by a national undergraduate PEOLC curriculum. There are shared concerns around gaps in content, minimal formal assessment, and limited contact with specialist palliative care providers. Lack of teaching staff and pressure on curriculum time are barriers to development. Participants showed modest self-efficacy and positive attitudes towards caring for those with PEOLC needs. Self-efficacy improved with education and frequency of exposure to PEOLC, whereas attitudes were more influenced by personal values, beliefs, attributes, and experiences.

Conclusion: Further curriculum development is needed to improve workforce capacity to increase access to primary palliative care. These results may be used to influence undergraduate education to ensure graduates are prepared to meet the palliative care needs of the population into the future.

Conflict of interest: none

ID: 192
Abstract Type: Poster

Topics: Relationships and connection, Networks and compassionate communities

Keywords: Goals of Care, Patient Care Planning, Communicaiton, End of Life Care

'Wanting to be Heard' – A Qualitative Study of Patients' and Nominated Healthcare Spokespersons' Experiences of Goals of Care Discussions in Acute Care

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Background: When patients are at the end-of-life, Goals of Care (GOC) discussions allow healthcare providers to align medical care with the expectations of patients and their families. The challenges faced by healthcare providers who conduct GOC discussions are well described, but there is little understanding of the lived experiences of patients and their Nominated Healthcare Spokespersons (NHS) who participate in the discussion. In-depth analyses of their experiences will provide insight to improve the conduct of GOC discussions.

Objectives: The primary aims are to identify (1) the features of a well-conducted GOC discussion and (2) the elements that facilitate a consensus decision between patients, NHS, and the healthcare provider.

Design: A qualitative inquiry method led by a grounded theory methodology, employing a social-constructivist approach and interpretivist research paradigm.

Method: Participants were purposively sampled from the medical oncology, geriatric, and palliative medicine department of a single tertiary hospital based on sociodemographic data and disease trajectory. Data was gathered using semi-structured interviews until theoretical saturation was reached. 20 interviews (7 patients,13 NHS) were conducted. All participants are patients or NHS of patients who have life-limiting illness (10 cancer, 10 non-cancer), with varying prognoses from 3 months to 1 year.

Results: The analysis yields 2 major themes – (1) Desired Communications Skills, (2) Preconceived Health Perceptions – and 6 subthemes – (1a) Mitigating Complexity (1b) Respecting Autonomy (1c) Empathy, (2a) Trust (2b) Existential Struggles (2c) Health Perceptions. In well-conducted GOC discussions, healthcare providers are expected to mitigate the complexity of medical care, respect autonomy by recommending therapeutic options, and demonstrate empathy. A consensus is easily reached if the participant gives deference to the opinion of healthcare providers, engages in existential struggles, and is accepting of their medical condition. It is difficult to reach consensus if the participant harbors mistrust towards healthcare providers, avoids existential struggles, and has a perceived sense of invincibility regarding health.

Conclusion: Communication skills such as mitigating complexity, respecting autonomy, and displaying empathy, are foundational to well-conducted GOC discussions. Identifying and addressing the preconceived health perceptions of the participant will help to reach consensus.

ID: 193

Abstract Type: Oral presentation

Topics: Policy and advocacy, Educational approaches

Keywords: public information, education tools, public health, end of life, palliative care, communication

Development of public information and education tools on end-of-life and palliative care

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Background: The Centre National des Soins Palliatifs et de la Fin de Vie helps to analyze the multiplicity of end-of-life situations and produces expert reports. Its mission is to promote access to rights and improve end-of-life care in France by encouraging public dialogue, societal and ethical debate and shared decision-making processes between citizens, patients, families and professionals.

Objectives: Develop educational tools to help users better understand and exercise their rights at the end of life, and provide them with all the information they need. These tools should make it easier to answer their questions throughout their life course, while ensuring that they are adapted to the specific needs of each audience.

Design: Design based on a participatory methodology involving members of expert commission, mirror group (users), scientific and institutional partners specializing from epidemiology, legal data, medical, public health, human and social sciences, and patient representatives. This process of co-constructing evidence-based tools applies to both the content and form.

Methods: For each project, multidisciplinary working groups are led by the National Center, with stakeholders including users to review all the information and ensure that content meets quality criteria. The Centre's team has a wide range of skills in health communication and graphic design to produce appropriate tools (computer graphics, websites, brochures, videos, podcasts, articles, etc.).

Results: We have developed an information portal for all audiences (professionals, patients, relatives) : www.parlons-fin-de-vie.fr, including an interactive map of palliative care services available at the end of life to locate the nearest palliative care facility, a 'Frequently Asked Questions' section based on questions from citizens, and various leaflets, infographics, podcasts and reports such as a national atlas of data on palliative care and an overview of active aid in dying around the world.

Conclusion: With its mission of information and education of the public, the National Center contributes to strengthening the knowledge of all citizens on the end of life and palliative care and encouraging the involvement of stakeholders in improving healthcare and socialcare pathways.

Conflicts of interest: none

ID: 194
Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: compassionate community. palliative care. social connections. supporting. Mutual helping

Developing Compassionate Community with 'community connectors'

Kaori Yoshida
Haruka Community Palliative Care Support Center

Social connection is essential to human well-being. To live a good life one needs mutual help and support from others, especially when faced with aging, serious illness or other troubles. In the city in northern Japan where I work as care manager, however, demographic aging is going on in a significant manner and the elderly people in growing numbers are socially isolated with the high percentage of elderly and single-person households. In addition there are those residents who relocated from east coastal areas after the 2011 East Japan Earthquake and subsequent. They often lack social connections. This leads to hinder not only cooperation and mutual assistance at the time of disaster but individual inhabitant's good life.

For the past 18 years, I've been leading a community project, based at local community palliative care support center, to foster 'community connectors' who accompany individual patients and families as well as palliative care volunteers. The training curriculum emphasizes the importance of experiencing the presence of the others with one's mind and body. Developing compassion and new relationships, future 'community connectors' learn to act on their own initiatives. They support patients and families, take part in rehabilitation programs, and share treasures of local community with multi-generational and multinational residents.

Our continuous efforts bear fruit of compassionate community and manifold social network. Mutual helping and supporting relations are built. When some patients find it challenging to go out, 'community connectors' visit their home and sing their favorite songs together. In times of bereavement, community members gather together to remember the dead, with Buddhist sutra chanted by terminal cancer priest who once suffered with alcoholic dependence. Some 'community connectors' host amateur singing contest with local residents, inviting people with multi-generational and multinational backgrounds including home care patients, care facility residents and those who moved from disaster affected areas. By remembering each life of fellow companions and expressing their own feelings in words, they get emboldened to live their own lives. By supporting others, they realize that they are also supported. We thus witness the emergence of compassionate community.

ID: 195
Abstract Type: Workshop

Topics: Networks and compassionate communities

Keywords: Compassionate Communities, Japan, international partnership, rural areas

Emerging compassionate communities in Japan and international partnership

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In Japan, demographic aging and decrease in population are going on in a significant manner. Social isolation of the elderly is one of the most serious social issues with changes in household structure. In rural areas it is difficult to secure enough medical professionals and caregivers with population concentration into major cities. New social ideas are needed to modify the governmental policy measure ‘community-based integrated care systems’ and the idea of Compassionate Cities and Communities (CC) is attracting more attention.

Against this background we will share the ideas and practices of emerging CC in rural areas in Japan and their partnerships with CC in England. Participants, who are interested in community building in rural areas or exploring initial stages as well as current state of CC in non-European or East Asian contexts, will enjoy opportunities to enhance their understanding of CC and meet with new partners.

Compassionate Communities Japan (CC-JP) was launched at the Japanese Society for Hospice and Home Care Conference in October 2023. There is now a CC-JP network meeting virtually each month with over 30 regular participants and several areas of Japan are starting to get involved in CC-JP activities. There is also a growing movement of CC-JP for Young Adults who recognise the importance of compassionate communities for their age group too.

This proposed workshop consists of 4 short presentations, followed by dialogues with participants. The introductory presentation will be delivered by a Japanese philosopher, who translated Allan Kellehear’s *Compassionate Cities, Public Health and End-of-life Care* into Japanese in 2022. In the second presentation the mayor of a small town will share the basic ideas and experiences to develop the first compassionate town in Japan. In the third presentation social worker of local community palliative care support center will share her path-breaking CC activities getting patients, (bereaved) families, friends, and neighbors involved and encouraging social sectors to take part. The last presentation will be delivered by the Development Director of CC-UK, who has initiated a learning exchange between compassionate cities/towns in UK and Japan. At the end we will have dialogues with participants on initiating CC in non-European social-cultural contexts as well as the significance of cross-cultural CC partnership.

ID: 196

Abstract Type: Poster

Topics: Policy and advocacy, Research methods

Keywords: Homelessness, Co-production, Research

Reflections on co-producing palliative and end of life care research with co-researchers with lived experience of homelessness

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Background: Co-production of research aims to recognise the unique expertise of people with lived experience (PWLE) and integrate this knowledge meaningfully within the research. Recently, there has been increased co-production of palliative and end of life care (peolc) research. However, PWLE homelessness are rarely included in co-production of peolc research. Given the disparately low rates of access to palliative care services against the high level of need in this population, PWLE homelessness are a critical group to engage in co-production of palliative care research. The authors recently developed and published the TIFFIN guidance to support co-production of peolc research with PWLE homelessness, from which the current abstract stems.

Objectives: To provide a dual-perspective reflection on co-producing peolc research with co-researchers with lived experience of homelessness.

Design: This reflection forms part of a larger qualitative study.

Methods: We worked alongside an independent homelessness peer advocacy organisation in the

UK to recruit a lived experience co-researcher. They were a member of the core research team, and co-developed study materials, recruitment of participants to the larger study (health and social care professionals and people with lived experience of homelessness). They also played a role in collecting qualitative data via interviews and focus groups, data analysis and dissemination of the findings from the qualitative study. Throughout the current study, there were two main forms of data collection: weekly one-to-one debriefs held between the PI and co-researcher, and reflective diary writing from the PI and co-researcher.

Results: Both debrief conversations and diary entries will be analysed using thematic analysis. This abstract will subsequently report on the experiences, successes and challenges of being and involving a lived experience co-researcher from a dual perspective.

Conclusion: Co-production of peolc research with PWLE homelessness is a crucial area, currently in its infancy. This study allows dual-perspective exploration of the experience of co-research in this field, to inform, improve and advocate for future co-production.

ID: 197
Abstract Type: Oral presentation

Topics: Policy and advocacy, Educational approaches

Keywords: Bereavement, School, Grief education

Evaluation of the teacher training phase of the School Bereavement Programme in Northern Ireland

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Background: Northern Ireland (NI) demonstrates a comparatively low level of engagement in addressing and discussing matters related to death and dying. This occurs even though approximately 1,600 children are bereaved of a parent/carer each year in NI - at least 1 child in every classroom. There is growing evidence that avoiding this subject with children can increase the risk of poor mental and physical health, yet half of children had not received support from their school or college after a bereavement. Marie Curie, a leading end-of-life care charity in the UK, partnered with Cruse Bereavement Support charity to fill this gap in NI through a school bereavement training programme focussed on equipping teachers to support children in the educational setting.

Objectives: To examine the impact of the school bereavement training on the confidence and knowledge of the teaching staff, impact on pupils, changes in school policy and practice since the training, and the barriers and enablers of impact.

Design: Mixed-methods service evaluation comprising a survey and semi-structured interviews.

Methods: Nineteen qualitative interviews with teaching staff (of children aged 4 – 16), plus five bereavement trainers. Interviews were analysed using reflexive thematic analysis, building on themes identified in an earlier pilot phase of the training. Pre-post training survey results will be analysed using a Mann-Whitney U test for significance.

Results: The training programme was attended by 372 teachers from primary and secondary schools across Northern Ireland. Reflexive thematic analysis highlights that teaching staffs' confidence, knowledge and ability to support pupils increased post-training. The bereavement training helped to break down social taboos around talking about death and dying, including supporting the prioritisation of grief within the school ethos. Examples of shared learning, changes to practice and policy development and improvement were given. Statistical analysis is underway at the point of submission.

Conclusions: Training teachers to support children aged 4-16 in the school environment who have experienced loss and bereavement had positive outcomes for both teaching staff and pupils. Greater investment and rollout of such training has clear benefits, and could impact wider policy, guidelines and prioritisation of grief education within the school curriculum in Northern Ireland and beyond.

ID: 198
Abstract Type: Poster

Topics: Research methods, Educational approaches

Keywords: Advance care planning, evaluation, meta-review

Evaluating outcomes of ACP interventions for adults living with advanced illness and people close to them: a meta-review

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Marie Curie, United Kingdom

Background: Advance care planning (ACP) is intended to assist individuals in articulating, discussing and documenting their future medical care goals and preferences. Existing evidence has reviewed barriers facilitators and benefits for ACP. However, a recent editorial exposed a potential disparity between the intended outcomes of ACP and its actual impact, highlighting a potential rift between theoretical ideals and real-world decision-making. This lack of clarity is occurring despite a high level of financial investment into ACP through grant funding, relative to other areas of palliative care.

Objectives: To explore how current ACP interventions are evaluated in systematic reviews globally, including whether those identified are achieving their intended outcomes.

Design: A meta-review of existing systematic literature reviews.

Methods: Keyword searches across five electronic databases identified key systematic reviews for inclusion. To be eligible for inclusion, papers must report a review of any design, include discussion of an ACP intervention (including any global term for any ACP intervention) and its outcomes for adults with advance illness. ACP outcomes for this review are informed by a 2018 Delphi study, summarising 'outcomes that define successful advance care planning'. Two Patient and Public Involvement representatives form a core part of the research team; their involvement includes protocol development, abstract writing, screening, and future data analysis. Their involvement is planned and tracked through the PIRIT tool.

Results: Database searches identified 1552 potentially eligible records. At present, 74 full texts are being screened. The full protocol can be found on PROSPERO. During the conference we plan to be able to present analysis addressing the following research questions:

1. How are current ACP interventions evaluated?
2. Do current evaluations suggest that advance care planning is achieving its intended outcomes?
3. Do the above results differ by population?

Conclusion: By consolidating global review evidence, this meta-review has the potential to provide more comprehensive understanding of current achievements, remaining gaps and challenges of ACP. This enhanced insight can better inform the direction of research and funding, aiding health and social care professionals to meaningfully utilise ACP interventions for better end of life care.

ID: 199
Abstract Type: Oral presentation

Topics: Care in humanitarian contexts

Keywords: Palliative care, early palliative care, qualitative research, communication, narrative.

Patient perspectives on conversations with healthcare professionals about life in the context of serious illness and palliative care

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Background: A challenge for palliative care is the general perception that palliative care is equal to end-of-life care. This can make healthcare professionals hesitant to initiate conversations about early palliative care and life in the context of serious illness. There is therefore a risk that health care professionals postpone the introduction of palliative care to the very end of life.

Aim: To describe and interpret patients' experiences and preferences for conversations with healthcare professionals about life in the context of serious illness and palliative care

Design and method: Qualitative design. Participants were recruited at a specialized palliative care unit and a hematology unit at a university hospital in Sweden. Twenty-seven people (45-84 years) have given their consent to participate and the interviews were conducted in the participants homes or at the hematology clinic. The transcribed audio recordings have been preliminarily analyzed qualitatively descriptively and will now, after the data collection is completed, be analyzed more thoroughly with phenomenological hermeneutic analysis.

Preliminary results: According to the patients, conversations about severe illness with healthcare professionals were mainly about disease specific medical treatments. Conversations about the future, symptom relief, family support and places of care were mainly exemplified in conversations with palliative care specialists. Several patients say that health professionals must be sensitive to when the patient is receptive personally, in order to offer well timed conversations. Trust in the person the patient talks to about such issues is emphasized as more important than the person's profession. The concept of palliative care was perceived by several participants as a loaded word and something that did not yet apply to them. Rather, they said that palliative care will apply later when they need hospice care. Many participants wanted more knowledge about available support when disease specific treatment is no longer possible.

Discussion: The participants examples of topics in conversations with professionals were dominated by treatment related issues and most likely framed by treatment. There is a particular need for professionals to invite the patient to talk about uncertainties, the future, preferred places of care and what is particularly matters to them.

ID: 200
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Research methods

Keywords: Implementation science, Bereavement care, Evidence-based practice, Intervention adaptation, Contextual analysis

Use of implementation science to tailor evidence-based BEreavement SupporT to families in Swiss specialized palliative care: The BEST for Family Project

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Background: Two decades ago, the three-tiered bereavement support model was put forward to improve family access to compassionate care that addresses individual needs and capacity-risk profiles. Integration of such evidence-informed bereavement support into Swiss palliative care (PC) services has been slow and fractional.

Objectives: To implement and sustain evidence-informed family bereavement support in two specialized PC services, using implementation science methods.

Design: Multimethod approach, combining intervention adaptation, qualitative contextual analysis, and implementation mapping.

Methods: Adaptation of evidence to local contexts was guided by community engagement and the ADAPT guidance, and occurred through evidence synthesis, two co-design workshops with 18 PC staff, and consultation with bereaved families. To identify barriers and enablers, a contextual analysis, guided by the Consolidate Framework for Implementation Research, was undertaken, using two focus group interviews (n=14 PC staff). Implementation mapping guided the development of a tailored implementation plan.

Results: Intervention adaptation activities resulted in a bereavement support pathway with three core components, namely assessing family situation, needs, burden, and risks; providing tailored information, communication, and support; and ensuring continuity and coordination through collaboration and referrals, delivered over four time-points (dying phase to one-year post-loss). Six domains were found to potentially influence its implementation, namely features of the intervention, staff competencies, resources, workplace culture, organizational preconditions, and project nature. Sixteen discreet implementation strategies were chosen to minimize barriers and capitalize on enablers, such as: train and educate, revise professional roles, redesign workflow, support clinicians, build on palliative care culture, or create a supportive local community. An implementation plan with a research logic model was developed in close collaboration with key partners from the PC services, which will guide actual implementation.

Conclusions: The use of implementation science methods enabled early engagement of the interprofessional PC teams and a systematic development process, which resulted in an evidence-informed bereavement support pathway and tailored implementation plan fitting to local and cultural conditions. Evaluation of the actual implementation success will now be necessary.

ID: 201
Abstract Type: Poster

Topics: Care in humanitarian contexts

Keywords: Palliative care, person-centred palliative care model, review

Person-centred palliative home care from patient- and carer-perspectives – a scoping review

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Background: Patients approaching end of life often express a desire to spend their last months – and even die – at home, if given appropriate support. Thus they may benefit from palliative care at home. To support patients to live as well as possible in end of life, the 6S model for person-centred palliative care has been developed in Sweden.

Aim: To summarize and synthesize the literature regarding patients' and carers' perspectives of palliative care at home through the analytic lens of the 6S-model for person-centred palliative care.

Design and method: A scoping review was performed with PubMed, CINAHL, and Scopus (2008- June 2019) including twenty-four studies illustrating the perspectives of the patient (1), patients and carers (4) and solely carers (19). A qualitative deductive analysis was applied using the 6S model: *Self-image, Self-determination, Symptom relief, Social relationships, Synthesis* and *Strategies*.

Results: Palliative home care enabled patients and carers to maintain daily life, which strengthened their *self-image*. However, if carers' expectations of the healthcare system were unmet, it could be perceived as a threat. Adequate *symptom relief* was sometimes described as a prerequisite for palliative home care, as severe symptoms caused uncertainty and distress. Fulfilling the patient's wish to be cared for at home contributed to the experience of maintaining control: *self-determination*. Continuity and familiarity (including having family and friends around) was preferred when establishing relations with professionals. S*ocial relationships* were thus crucial to the patients and contributed to their wellbeing. *Synthesis* and *strategies* involved finding meaning in their situation and being able to share life stories. For carers, support from healthcare professionals was crucial, as they provided information about the patient's condition and the unfolding of the dying process.

Conclusion: Our results demonstrate that the dimensions in the 6S model are relevant for both patients and family caregivers when palliative care occurs at home. Database searches from more recent years are ongoing, which might modify the results.

ID: 202
Abstract Type: Poster

Topics: Death and grief literacy, Educational approaches

Keywords: healthy dying, education, nursing, palliative care

Healthy dying training for bachelor's students in nursing

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Background and objectives: Death is a universal experience; we created a course on "we all die, but how we die- that is the question". In this idea, a concept like empowerment is at the center of the approach – this approach is due to societal attitudes changes (Catford, 2018). Palliative care nursing focus for example on compassion care, dignity care and gratitude, however healthy dying is still new in the practice. Nurses have a key contribution to progress the community's perspective on healthy dying, through their role as care coordinators (Abel, 2018).

The aim of the poster will be to illustrate the approach of an optional course in nursing training on healthy dying from a community health perspective. We will present the content of the course and the reflections we had about "social representations", "health promotion and death – what synergies" and "community care and healthy dying".

Design and Methods: Creation of an optional teaching module as part of the final year of the Bachelor's degree in Nursing at HES-SO University of Applied Sciences and Arts Western Switzerland-Fribourg, using a health promotion and patient-centered approach to give students a change of perspective.

This module will be conducted over 5 days (1 week). It will start in January 2025 and will have three objectives:

- Conceive the link between health promotion and death, in particular by being able to explain the concept of "healthy dying" and "community care".
- Reinforce, in the context of palliative care, one's health promotion posture by developing a project.
- Develop a relational approach to health with the person in palliative care, in relation to bereavement and end-of-life issues.
- Examine the evolution of one's representations of death and health.

Results: In this course, students are divided into groups and are invited to carry out a reflection on a clinical vignette with a specific health dying context (nursing home, home care, community care, hospital).

This project-based approach enables the empowerment of their health promotion posture and a reflection around death and the patient needs. To encourage their success, the lessons give some information on the health systems partners and the state of the art of contextual practice of healthy dying.

Conclusion: The presented course on healthy dying gives the opportunity to empower nurses and patient needs.

ID: 203
Abstract Type: Oral presentation

Topics: The value of death

Keywords: End-of-life; care; survey; bereaved relatives

Findings from Ireland's first National End of Life Survey; a survey of bereaved relatives on care provided to family members and friends in the last three months of life

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Background: The National End of Life Survey is Ireland's first national survey to ask bereaved relatives about care provided to a family member or friend in the last months and days of life. The aim of the survey is to learn from people's experiences of end-of-life care in order to improve services provided both to people who are dying and to their loved ones, as well as to replicate areas of good experience across services and settings.

Methods: The survey was developed and implemented as part of a public partnership and the findings of the survey will be used to improve care provided at end-of-life. The survey design was based on reviews of comparable national and international surveys and extensive engagement with relevant stakeholders through Delphi Studies, a gap analysis, focus groups and cognitive testing.

The survey questionnaire contained 110 questions, three of which were open-ended and 107 of which were closed-ended. The survey captured experiences of care provided in the last three months of life in hospitals, hospices, nursing homes and the home. Questions regarding the standard of coordination between services and healthcare staff who cared for a person in the last three months of their life were included.

A communications plan was successfully implemented to maximize the survey's response rate. This included raising awareness of the survey via social media, information webinars and radio advertisements.

Results: 9,446 bereaved relatives were invited to participate in the survey, of whom 4,570 bereaved relatives chose to take part, representing a 48% response rate. Findings indicate that the majority of respondents reported that their family and friends were treated with respect and dignity. However, respondents also reported that the care provided could been coordinated better, both across and within services and settings where they received end-of-life care.

Conclusion: The survey represents the first standardised national approach to capturing and using the experience of bereaved relatives to improve end-of-life care in Ireland. The findings of the survey will provide healthcare professionals who are planning and delivering end-of-life care with evidenced-based data on what works well and where improvements are needed.

ID: 204

Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, Artistic and creative approaches

Keywords: LGBTQ+, Arts-based approaches, barriers to care

"It's more than rainbows in receptions" -

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Background: Lesbian, gay, bisexual, transgender, queer and other gender diverse (LGBTQ+) people experience healthcare inequity due to discrimination, assumptions made by healthcare workers and anticipating discriminatory behaviour. It often may not feel safe to access screening programmes and ignored symptoms may result in late diagnoses, advanced illness, and delayed referral to palliative care. Previous negative experiences frequently create societal exclusion and a fear of rejection related to gender, identity, or sexual orientation.

In recent years rainbows and pride flags displayed in healthcare environments have suggested a movement toward inclusive care. However, it goes beyond well-meaning gestures to better understand the principles of equitable palliative care for LGBTQ+ people.

Objectives: We sought to explore the experiences and concerns of LGBTQ+ people accessing palliative care and provide a safe environment to think about priorities for future care. We recognised the need to co-develop a resource to increase healthcare workers awareness and curiosity of LGBTQ+ inclusive care.

Design: 9-month qualitative study

Methods: This was an equity-oriented study directed by the values of co-production and involved the recruitment of 10 LGBTQ+ people and allies. Arts-based methods used for community workshops were delivered by LGBTQ+ facilitators and data analysed using reflexive thematic analysis.

Results: LGBTQ+ people continue to feel excluded from palliative and wider healthcare services with previous experiences adversely impacting how people feel about accessing care; often hiding their identity or holding negative perceptions of their own end-of-life care.

"Other patients were homophobic; the Hospice and some staff aren't prepared to take it seriously."

Results shared through the voices and illustrations of LGBTQ+ people will be presented at conference and a co-designed resource will be internationally launched.

Conclusion: This study found evidence that the barriers experienced by LGBTQ+ people are significantly likely to influence, challenge and disrupt the decisions made when planning for end-of-life care and access to palliative care. Research grounded in co-production and viewed through the lens of people with lived experience is fundamental to addressing inequity in palliative care.

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ID: 205

Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: Pediatric palliative care; Pediatric palliative nursing; Complex care management; Interprofessional comprehensive care

Pediatric Palliative Care – building bridges between hospital and community care for child and family

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Background: Pediatric Palliative care focuses on providing relief from symptoms and stress of a life-limiting illness. The goal is to improve quality of life for both the child and the family. Pediatric Palliative Care can take place prenatal if a child is diagnosed with a life limiting illness before birth. Most of the children which receive Pediatric palliative care are diagnosed with a rare disease and therefor have an unknown live expectancy.

Objectives: The goal of this pragmatic cases series practice development project is to demonstrate, how successful pediatric palliative care with a family integrated focus can be performed when health care staff in the hospital and community setting are collaborating in a partnership for care.

Design: A pragmatic case series practice development project serves to define a comprehensive patient journey for successful pediatric palliative care to support the collaboration of community and hospital based health care professionals.

Methods: A pragmatic case series practice development project serves in a pediatric palliative care setting to define successful partnerships between health care professionals in different health care settings as well as patients and families to enhance a partnership for care in pediatric palliative care settings.

Results: Based on this small case series we demonstrate different paradigm and how to implement these in daily practice to enable successful pediatric palliative care on a family integrated focus in the hospital as well as the community setting. We elaborate key factors to support a comprehensive continuum of care which focuses on enabling patients and families based on their individual needs.

Conclusion: Pediatric palliative care needs to be implemented long before end of life care of a child and has the power to build bridges between different health care settings. They further enable a family integrated care model which supports a partnership in health delivery for child and family.

ID: 206
Abstract Type: Poster

Topics: Policy and advocacy

Keywords: Opioids, policy, scoping review

Understanding how policies impact global access to and safe use of opioid medicines

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Background: Many regions of the world suffer from insufficient access to essential opioid medicines for pain relief and palliative care. Concurrently, however, opioid-related harms contribute to significant global morbidity and mortality. To address these parallel issues, there is a need for a theory-informed synthesis of opioid policy evidence that explores the mechanisms through which policies impact both opioid access and safe use.

Objectives: To delineate the range of policies that influence access to and/or safe use of opioid medicines; to map the components and characteristics of these opioid policies and categorize them according to their mechanisms of action; to produce a conceptual framework that outlines the various policy mechanisms available for governing access to and safe use of opioids.

Design: We will conduct a scoping review of the academic and grey literature based on guidance from the Joanna Briggs Institute. The guiding question for this review is, “What are the policy mechanisms that are used by policymakers to govern access to and safe use of opioid medicines at an international, national, and regional level?”

Methods: We will develop a logic model to guide the review by adapting a published template with relevant concepts and frameworks from the fields of public policy and program evaluation. We will conduct a single search using terms related to ‘opioid medicines’ and ‘policy’. Eligible records will describe one or more policies that govern the selection, procurement, distribution, or use of opioid medicines. We will code all eligible records to develop a typology of opioid policy components and characteristics using a “best fit” framework synthesis, with our logic model serving as the initial coding framework.

Results: Outputs from this review will include a categorized list of opioid policy evidence, as well as themes relating to the main components and characteristics of opioid policies. These themes will be used to create a framework of opioid policies based on mechanisms of action, components and resources of associated programs, policy aims, target populations, and relevant pharmaceutical system dimensions.

Conclusion: This review will provide a summary of opioid policy evidence across various settings and will highlight current gaps in research. It also will produce a conceptual framework of opioid policies that can be used for guiding subsequent systematic reviews and qualitative evidence syntheses of opioid policy research.

ID: 207
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Networks and compassionate communities

Keywords: Places of Solace, Community Support, End-of-Life Care, Grief Normalization, Compassionate Communities

Places of solace: a starting point for a Compassionate Community?

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Background: Advocates for a community-centric approach to palliative care have highlighted the pivotal contributions of informal community networks, arguing that a substantial part of the end-of-life care and support is rooted in community interactions. These networks, often consisting of friends, family, and neighbors, are instrumental in providing both emotional and practical support to those facing serious illnesses and loss. Nevertheless, societal taboos surrounding end-of-life discussions impede openness, confining many of these conversations to professional care environments. A recent groundswell of movements and organisations is rising in Flanders, Belgium, stimulating engagement with serious illness, death, and bereavement. Although there has been a positive development in relation to the taboo surrounding loss and grief in public settings, there is still limited understanding of how people perceive and use places of solace.

Objectives: Our study aims to delve into the lived experiences of people using places of solace when faced with serious illness, death, or grief. The main research questions guiding this inquiry are: 1. What meaning do individuals attribute to places of solace? and 2. What role do these places fulfill within a neighborhood?

Design: Through a mixed-methods approach, existing out of 6 focus groups and an online survey for visitors and a subsequent survey was tailored for the coordinators.

Results: The results illuminate their role as sanctuaries for peace, mediums for the reciprocal exchange of solace, and arenas for normalizing discussions on death and loss. Places of solace foster community ties, enhancing public discourse and social cohesion around end-of-life issues. Findings suggest these sites serve both personal reflection and collective experience, challenging societal norms and promoting resilience.

Conclusion: This study serves as a clarion call for the acknowledgement of the importance of places of solace and integrate them into their initiatives and policies. It beckons policymakers, organizations, and communities to integrate these spaces into their frameworks, fostering environments rich in care, compassion, and collective well-being, particularly during life's most challenging moments, such as times of serious illness, caregiving, dying, and loss.

ID: 208

Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Research methods

Keywords: healthcare access; cancer; health equity; community engagement

Co-development of recommendations to improve access to care for structurally marginalized people with life limiting cancers: process and outcomes

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Background: People who experience structural marginalization are dying of preventable and treatable cancers because they cannot access the care and treatment that they need. Research suggests that such groups are not well-served by cancer services, and rarely, if ever, are cancer services designed to meet the needs of people experiencing structural marginalization. Organizational and systems-level changes are required to support approaches to cancer care that are equity-oriented.

Objectives: To engage people experiencing structural marginalization and their care providers in the co-development of evidence-informed recommendations to improve access to cancer services, and to increase capacity for equity-oriented cancer care.

Design & Methods: As part of a larger study informed by critical ethnographic methods, we conducted focus groups and semi-structured interviews with people experiencing structural marginalization (n=28), community-based health and social care providers (n=16), and clinicians and leaders in cancer care (n=16). Data collection included iterative cycles of engagement with participants and community members, where we

(1) asked questions regarding how to make cancer care more equitable and accessible and (2) co-developed a set of recommendations for cancer care organizations. Data analysis followed an interpretive descriptive approach.

Results: This process resulted in multiple recommendations, including action-oriented strategies and tangible examples. For example, one recommendation was that careful attention be paid to service design to ensure that services are maximally accessible for people experiencing structural marginalization. This could include implementing collaborative models of care that better support social needs, such as instituting complex case rounds in collaboration with community-based services or cross-sectorally to support temporary accommodations for patients who are unstably housed and with otherwise not be able to receive cancer treatment.

Conclusion: Iterative processes of data collection, analysis, and community engagement resulted in the co-development of several evidence-informed, action-oriented strategies for cancer organizations to improve capacity for equity-oriented care. If implemented, these community-informed public health approach recommendations could improve access to and experiences of cancer care for structurally marginalized populations.

ID: 209

Abstract Type: Poster

Topics: Research methods, Care in humanitarian contexts

Keywords: home caregiving preparedness, communication, palliative care, spiritual well-being, rural Appalachia

Association of preparedness and palliative care communications with spiritual well-being of family caregivers of patients with vascular dementia

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Background: This is a follow-up study based on caregiver's description of their spiritual well-being as related to home care management for patients with deteriorating heart failure (HF), dementia, and palliative care needs. Dementia and heart failure (HF) are the most common co-existing end-of-life conditions among older adults requiring extensive home caregiving. Spiritual well-being sustains family caregivers during times when their loved ones are experiencing deterioration, entering palliative care, and facing death. The rural Appalachian population values spiritual well-being.

Objective: This study aimed to assess the factors impacting the spiritual well-being of caregivers in the rural Appalachian region.

Design: This study used a descriptive correlational design. Caregiving Preparedness Model is used to guide this study.

Methods: Data was collected from adult caregivers (N=20, age 18 and older) of loved ones with the diagnosis of HF and dementia (age 55 and older) in Rural Appalachia. A multiple regression analysis was performed on caregivers' spiritual well-being scores as the dependent variable. Factors impacting caregiving: 1) caregivers' preparedness for HF and dementia home care and 2) patients' physical, emotional, and palliative care needs were the independent variables.

Results: The average age of these family caregivers was 64.95 years (SD =12.42). The average length of home caregiving for HF was 6 years (SD = 4.97) and 4.29 years (SD = 4.82) for dementia These caregivers median score on the spiritual well-being scale was 32.5 out of 45. In the regression analysis, a large amount (53%) of variance in spiritual well-being was explained by caregivers' greater preparedness for HF and dementia home care (β =.53, p <.01) and by informational communications about caregivers' practical palliative care concerns (β = -.70, p <.05). These caregivers age, years of caregiving, and patients physical and emotional status did not statistically contribute to caregiver spiritual well-being.

Conclusion: This data supports nurse-led interventions for HF and dementia home care preparedness. Regardless of caregivers' age, years of care, and health status, nurses can communicate information on managing in-home care practical concerns. Nurses may also support caregivers' spiritual well-being by increasing caregiving preparedness by holding supportive caregiver discussion groups and setting up home visits and telephone contacts with their spiritual advocates.

ID: 210
Abstract Type: Poster

Topics: Policy and advocacy

Keywords: palliative care, policy, cancer, non-cancer, document analysis

Inclusion of palliative care in Swedish national policy documents for care of severe chronic conditions and cancer

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Background: The inclusion of palliative care in policy has been encouraged internationally, and gradually implemented in Sweden. Previous research shows differences in care at the end of life between different severe chronic conditions as well as between different cancer types. Care is driven by policy and to the best of our knowledge the inclusion of palliative care in Swedish policies has not been systematically reviewed previously.

Objectives: The objective of this study was to examine how palliative care is included in Swedish national disease-specific policy and guideline documents to illuminate prevailing ideas and assumptions regarding palliative care.

Design: Document analysis.

Methods: A document analysis of Swedish policy and guideline documents for care of different disease-specific groups (severe chronic conditions; cancer and non-cancer) was performed. In total 141 documents were analysed for descriptions referring to palliative care.

Results: Large variations were identified in the ways palliative care was included in the policy documents, and it varied from mentioning the term without explications to elaborations of palliative care practice. Further variations encompassed disease-specific palliative treatments (e.g. anti-tumoral treatments), care of the dying, referring to established definitions (e.g. WHO:s definition), an integrated care approach, and family support.

Conclusion: There are large variations in how palliative care is included in Swedish national disease-specific policy and guideline documents. The inclusion of palliative care is limited to disease-specific palliative treatments and care of the dying person, which delimits its scope in ways that are contrary to current evidence for early integrated palliative care. A lack of palliative care recommendations adapted for each specific diagnosis indicates a gap in policy. The current ways of including palliative care in national policy documents needs to be acknowledged and discussed to promote facilitation of equal access to palliative care across diagnoses.

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ID: 211
Abstract Type: Poster

Topics: Policy and advocacy

Keywords: policy, governance, organisation, palliative care, cancer

Governance and organisation of palliative care in cancer care in Sweden - cancer care leaders' perspectives

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Background: Governance and organisation of care is driven by policy and inclusion of palliative care in policy has been encouraged

internationally, and gradually implemented in Sweden. However, governance and organisation of palliative care in cancer care in Sweden has not been systematically reviewed previously.

Objectives: The aim of this study was to investigate cancer care leaders' perspectives on governance and organisation of palliative cancer care in Sweden.

Design: Qualitative design.

Methods: Participants in this study were leaders and patient representatives in the national cancer care organisation for different cancer diagnoses, including palliative care, and heads of regional cancer centres. They were identified through regional cancer centres' websites, policy documents for cancer care and websites from national patient organisations. In total 157 leaders were invited to participate in an interview, and 36 participated in 16 interviews; ten individual and six group interviews with 2-6 participants in each.

Results: Governance and organisation of palliative care was seen as primarily performed on an individual and local level, rather than regionally or nationally – large differences locally within regions were described, however differences between regions were also stressed. A scarcity of national governance for palliative cancer care was voiced, and a more nationally aligned governance and organisation with a minimum standard for palliative care was called for. Discussions were about continuation of oncological treatments late in patients' trajectories, which hindered early integration of palliative care and the possibility of dying at home. Specialised palliative care was expressed as care of the dying and although general (non-specialised) palliative care was not clearly defined, it was expected to be provided by all healthcare professionals. Furthermore, the discussions were about prevailing lack of knowledge and reluctance towards palliative care amongst the public and clinicians.

Conclusion: The result indicates that national prerequisites for palliative care varies in ways that may hinder equity in palliative care. National governance and a nationally equivalent organization with strategies and minimum standards to enable palliative care according to patients' preferences are called for. The possibility to die in one's preferred place, and especially at home, requires knowledge about palliative care and early integration of palliative care.

ID: 212
Abstract Type: Oral presentation

Topics: Relationships and connection

Keywords: Palliative care, Low socioeconomic, recruitment, integrated knowledge translation.

Bridging the gap: Strategies to engage under researched and underserved populations in palliative care research

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Background: Palliative care is not equally available to all Australians. Although research can address gaps in palliative care service and delivery to underserved populations, participant recruitment is difficult, especially amongst resource poor populations with little engagement in mainstream health services. Unless researchers build sustainable trust relationships with low socioeconomic populations, these groups will remain under researched and underserved. This presentation will illustrate practical strategies to reach, enable and build sustainable relationships between researchers and low socio-economic populations with the purpose of engaging these populations in research to improve palliative care services and delivery.

Objectives: To increase the inclusion of low socio-economic populations in palliative care research.

Design: This study is part of a larger 5-year South Australian research program addressing deficits in accessing palliative care for underserved communities. The research program takes a public health perspective, underpinned by theories of integrated knowledge translation, co-design, and community engagement. Low socioeconomic research participants are identified as individuals who, over an extended period, live in a socially and/or geographically identifiable group impacted by lack of financial, educational, social, and health resources.

Methods: In line with underlying principles of integrated knowledge translation and co-design, participant recruitment involves employing deliberate strategies to build relationships and trust with the targeted population. This includes engaging in voluntary activities with community groups, repeat and sustained communication, face to face meetings onsite with prospective research participants and being flexible and responsive to community needs.

Results: Four community groups have committed to a study to improve death literacy within their communities and are implementing local, co-designed initiatives to build understanding of death and dying. Additionally, through the relationships established, recruitment of participants for a longitudinal study of end-of-life pathways is ongoing.

Conclusion: Recruitment of low-socioeconomic populations to longitudinal palliative care research is challenging, but possible. Through our experience with designing and deploying an integrated knowledge translation approach, this study demonstrates that a carefully crafted recruitment and retention strategy can be effective.

ID: 213
Abstract Type: Oral presentation

Topics: Death and grief literacy

Keywords: Grief Education, Grief Care, Medical Professionals, Group Intervention, Japan

Absence of grief care: Japanese medical professionals have no place to grieve

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Background: Medical professionals (MPs) in Japan have no educational or continuing professional training to deal with issues related to grief. The default coping mentality is to stay put ("ganbaru;" enduring the tough times) which prevents MPs from actively grieving. Grief Circle is a time-limited, semi-structured support group specially designed for MPs. Its goals include grief education, coping skills exercises, community building as well as empowering MPs to be grief educators at their own workplace.

Objectives: To examine the impact of Grief Circle program in 2023.

Design: Participants were mainly recruited through two mailing lists. Grief Circle met regularly over the topics including understanding grief, coping helping others and meaning making. This presenter facilitated all meetings.

Methods: Clinical observation, Grief Intensity Scale, questionnaire and self-report

Results: Among 24 participants who completed the program, 23 responded to the post-assessment and questionnaire. 96% of participants answered the program was extremely helpful and 100% answered the workbook was extremely helpful. While 4 participants reported that grief is impairing their daily routines on pre-assessment, one remained to be so after the program. 18 people reported to be comfortable with a group setting and 5 were moderately satisfied. All expressed the importance of grief support at their workplace and desire to commit to improve the grief support on multiple levels including personal and organizational.

Conclusion: The concept of grief is poorly recognized and grief care program is not even available for MPs in Japan. In addition, Japanese culture inhibits public expression of emotional needs such as grief. Despite these obstacles, Grief Circle was the first, innovative attempt to highlight the significance of grief awareness among MPs. And those who participated reported the high rating of understanding of grief, coping and self-awareness. These findings suggest that grief education as well as grief care need to be provided more widely in the Japanese medical community. This would enhance greater self-awareness and provide coping tools. In the world's fastest aging society, Grief Circle program will help develop a community of more compassionate caregivers.

ID: 214
Abstract Type: Poster

Topics: Death and grief literacy

Keywords: Death and dying, Institutionalization, Contemporary society, Social life, Bereaved

Institutionalization of death and dying in contemporary society: The changing landscape of the dying process in sub-Saharan Africa

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Background: The way in which death is experienced by the growing number of people in modern society represents a significant departure from the past. In the United States and many advanced societies, a significant majority of all deaths now take place in a public institution such as a hospital or long term care facility.[1]

Objectives: Institutionalization of death has been identified as a growing trend in sub-Saharan Africa. This study considers the changing landscape of the dying process in Contemporary society and it's effect on social life in sub-Saharan Africa.

Design: This cross-sectional study examined the effect institutionalization of death on contemporary social life in a community in sub-Saharan Africa. Participants were provided a questionnaire pack exploring their perceptions of the effects of institutionalization of the dying experience on their social life.

Methods: The 100 participants were bereaved families whose deceased relative had been admitted to a long term care facility prior to their demise. In order to guarantee an acceptable range of variability in the data set, responders were sampled from both public and private care institutions as well as from urban and peri urban settings.

Results: The study sample had a mean age of 47.8 years (standard deviation, SD=11.4) and largely comprised female responders (76.3%). The majority (67.8%) were married and 44% were either fully employed, self employed or retired.

35.6% complained about financial distress, 32.7% reported physical exhaustion and 27.1% felt socially isolated from their families (spouses). 20.3% experienced mental exhaustion, 11.9% had a feeling of helplessness while 5.1% felt that they had lost control of their households as a direct result of their involvement in the caring/dying process of their loved one.

Conclusion: The pervasive institutionalization of death and dying in contemporary society has had a destabilizing effect on social life particularly among recently bereaved families in sub-Saharan Africa. This study further advances our understanding of the devastating effect of the institutionalization of the dying process on social life in contemporary society.

Reference

1. Thorpe G. Enabling more dying people to remain at home. British Medical Journal, 1993;**397:**915-8.

ID: 215
Abstract Type: Poster

Topics: Artistic and creative approaches

Keywords: Art, Science, Faith, Death, Constructivism

The Facing-Death Project - A Community-Based Collaborative Art Initiative to Enhance End-of-Life Care Engagement: a pilot study

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Background: To enhance the quality of end-of-life experiences, fostering collaboration among key stakeholders is essential. The participatory art project could serve as a platform for such engagement. Our proposal aims for a relational engagement approach through art, complementing conventional research methodologies, gradually including the entire community and integrating scientific, professional, religious, and artistic perspectives.

Objectives: To examine the impact that art can contribute to society's attitude toward dying and death, we explored reactions of different professionals after art-based activities as part of the pilot study.

Design: Our study employs participatory action research, following a cyclic process of planning, actions, and observations. The project's core team, comprised of professionals and creatives, collaborated closely. Initially focusing on the core team, we are gradually involving the broader community. A pivotal element for this study was a photographic diptych portraying dying persons before and after death, with the person alive in the first photo, and his post-mortem portrait in the second - both portraits are placed in the same mirror-like, profile pose.

Methods: We identified key stakeholders in end-of-life care, including hospice volunteers, healthcare professionals, and funeral service providers, using a snowball sampling technique. Ad-hoc open-ended questions were used to elicit their reactions to art-based activities. Thematic analysis of open-ended questions was conducted.

Results: A total of 63 participants actively engaged in three professional roundtables and two workshop discussions, consisting of art presentations and discussions on various end-of-life topics. Their feedback was mostly positive, with descriptors like "meaningful" and occasionally "provocative" and "edgy," reflecting the perceived impact of art. Participants found the art inclusive, accessible, and often non-threatening, facilitating introspection, emotional responses, and initiating open discussions. Reflecting on their roles in end-of-life care, they noted personal significance.

Conclusion: Professionals exhibited immediate enthusiasm for art-based activities, reporting mostly positive effects. The potential of art to integrate relationships within the realm of death and dying was shown by our results, indicating its important role in fostering meaningful connections and addressing taboo subjects in the context of end-of-life care.

ID: 216
Abstract Type: Oral presentation

Topics: Artistic and creative approaches

Keywords: End-of-life narratives, spirituality, sense-making, ars moriendi, ars memorandi

Revisiting Ars moriendi and Ars memorandi. End-of-Life Narratives and spiritual Meaning and legacy-making in western european end-of-Life Care

Zoë Ghyselinck
Ghent University, Belgium

Background: This paper explores the growing trend of end-of-life (EOL) narratives in Western European EOL and palliative care. Dying individuals increasingly receive support from caregivers and biographers to review their lives and to pass down these stories to loved ones (Amfora, BE; Passeurs de mots, FR). The trend prompts us to rethink the changing ways in which the dying anticipate their afterlife among the bereaved. Research has emphasised the therapeutic benefits of narrative life-review for the dying, relatives and caregivers in EOL stages. However, little is known about the spiritual and cultural sense-making dimension of this narrative practice of legacy making.

Objectives: My study aims to understand how dying people navigate death, express values and communicate beyond the boundaries of death, by developing thoughts and hypotheses about the construction of narrative identities of the dying, on the one hand, and about the roles caregivers assume in assisting the dying to be posthumously witnessed by the bereaved, on the other.

Design-Method: The study is grounded in a literary and cultural studies perspective that values the EOL narratives both as narrative practices and textual objects at the intersection of narrative, spirituality and health care. Drawing on Ricoeur's concept of narrative identity and on scripts such as the Dignity Therapy Interview (Chochinov) and culturally shared stories of the dying (Frank 1993), the study assesses voice(s), temporal constructions and imaginative narrating in two recently published EOL narratives.

Results: My study shows how EOL narratives not only propagate a contemporary ars moriendi that negotiates palliative values such as dignity and autonomy in the dying process. They also propagate an ars memorandi that emphasises the influence the dying person seeks to have in the post-mortem phase. Furthermore, I will show that EOL narratives, although carefully structured and stylised, present a paradox that highlights the limitations of storytelling in capturing the raw reality of dying.

Conclusion: Drawing on the anticipatory underpinnings of this ars memorandi my study highlights the need to expand bereavement care during EOL stages. Given the stylized nature of EOL narratives influenced by biographers, I advocate for additional research that examines EOL narratives independent of guiding agencies and call for a nuanced and culturally diverse understanding of identity within the realm of EOL narrative practices.

ID: 217
Abstract Type: Poster

Topics: Networks and compassionate communities, Educational approaches

Keywords: Hospice, palliative, spiritual care, end-of-life care, Advance Care Planning

Compassionate Communities for All from Children to the Elderly throughout Japan

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Background: Japan has entered an era of declining population. In order for people to be able to live their last days in their familiar communities happily, healthcare professionals alone cannot cope with this situation. Non-professionals are expected to be able to practice end-of-life care.

Objectives: To reflect on the following practices. We developed an educational program to convey to non-medical practitioners the essentials of spiritual care needed to work with people in the final stages of life. We developed a system that promotes community development and continuous learning. The program then spread nationwide in a grassroots manner.

Design & Methods: The five elements that define spiritual care and interpersonal support in hospice and palliative care were identified, leading to the creation of the concept of ‘universal hospice mindset’.1. Listening with the awareness that people who are suffering greatly appreciate being understood (affirmative listening), 2. Inquire the person’s suffering and resolve the suffering that can be resolved, 3. Inquire the resources that allows the person to be calm despite the suffering that cannot be resolved, 4. Strengthen the person’s resources through dialogue, and 5. Know the resources of the caregiver himself/herself. An educational program has been created to learn these in a practical manner. We also provided support for community development that is based on continuous learning.

Results: From 2015 to December 2023, 175 sessions were organized. The program had 8,292 participants. 55 communities were spontaneously created nationwide as a result of participants becoming facilitators. Voluntary workshops have been held nationwide in various communities, such as local communities, medical and social work professional education, and others. By combining the workshops with other study groups that are related to recent government promotions, such as Advance Care Planning, synergistic effects have been generated The hospice mindset can be practiced by anyone and everyone, and Lessons of Life programs for both children and adults have begun a trainer certification program.

Conclusion: Learning communities have been created to practice the essence of spiritual care, and these communities are expanding their activities in partnership with various activities already existing in the community.

ID: 218
Abstract Type: Poster

Topics: Artistic and creative approaches

Keywords: advance directives, living will, terminally ill, Go Wish

The use of apps and games to increase the adoption of advance directives in Brazil: An Integrative Review

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Background: In Brazil, contact with palliative care and advance directives is limited during medical school, and palliative care was only incorporated into the medical curriculum at the end of 2022. Although advance directives are mentioned in the “Statute of the Elderly”, they are not widespread and face barriers due to the taboo surrounding the approach to death. Therefore, the research question is: “Does the use of playful strategies help to simplify and expand the adoption of advance directives in Brazil?”.

Objectives: To identify whether there are any playful strategies for dealing with advance directives, and to analyze their use, as well as the facilities and difficulties encountered in their use.

Design: The text was written according to the steps of an Integrative Review.

Methods: The study searched for articles in the BVS, Portal Capes, and Scielo databases, using the descriptors “advance directives”; “living will”, and “terminally ill”. 120 articles were found, of which 22 were selected after exclusion criteria and reading the full texts. Information from the website of the Brazilian Society of Geriatrics and Gerontology (SBGG) was also used.

Results: Given the global increase in the elderly population, the importance of respecting advance directives and principles such as autonomy and non-maleficence is evident. The actual implementation of advance directives faces legal challenges, a lack of knowledge, and prejudices about human finitude. SBGG has created an app to facilitate the elaboration of directives and launched a Portuguese version of the “Go Wish” game (2017). The “My Wishes” app (2020) aims to facilitate reflection and dialog about death-related wishes. At the end of the app, it generates an adaptable and shareable outline of the advance directives by guiding users through 5 steps. The “Cards on the Table” game consists of 36 cards, and it facilitates conversations about death-related wishes by categorizing them as: very important, more or less relevant and less important. It also has a special card for demands that are not covered.

Conclusion: About 4 years ago, the SBGG developed the "My Wishes" app and adapted the "Go Wish" game to simplify the discussion of advance directives. So far, there are no published results on the effectiveness of these approaches. Recent studies highlight the lack of knowledge on the subject, the need for specific legal regulation, and the urgency of cultural changes to overcome death-related taboos.

ID: 219
Abstract Type: Oral presentation

Topics: Networks and compassionate communities, Educational approaches

Keywords: hospice, palliative, spiritual care, compassionate community, children

Lessons of Life for School Children: What We can do to Increase Compassionate Individuals and Communities

Keiko Chida, Taketoshi Ozawa
End-of-Life Care Association of Japan, Japan

Background: The challenges faced by today's children include bullying, school refusal, self-harm, and suicide. It is not easy for school teachers to take care of children on their own. Different programs have been developed in different parts of Japan to convey the significance of life to children. The majority of them are led by individual trainers, and there are not many reports of systematic development of teaching materials, training of trainers, and classes.

Objectives: To demonstrate the way in which the Lessons of Life are established and implemented, so that children can comprehend and utilize the essence of spiritual care in their daily lives, which is cultivated in hospice and palliative care.

Design and Methods: The project was launched in 2018 as 'OK Project: The Lessons of Life'. The program was developed to aid children in comprehending the essence of spiritual care as conveyed to professionals. Lesson 1 is focused on acknowledging your resources through suffering, Lesson 2 is about what you can do when confronting those who suffer, and Lesson 3 is about affirming and valuing yourself. For children, three considerations were made (1) They were given familiar examples to personalize it by reflecting on past experiences. (2) Through the act of writing on the worksheet, they were able to clarify and visualize their personal resources. (3) An interactive format was used by the trainers to allow children to express their own ideas in an equal relationship. Trainers attempted to affirm children's remarks by saying 'you think so' even when they don't, regardless of their positive or negative tone. Through the interaction, the trainers themselves embodied the attitude so the children feel "I am glad to have someone who understands me".

Results: By December 2023, 203 trainers had been certified and delivered 490 classes to 60,098 participants. The reflection journal after classes showed a greater sense of self-affirmation and compassion for others. The reason for this achievement in such a short period of time is believed to be the improvement of easy-to-understand teaching materials, the development of a trainer certification system, support after trainer certification, and matching of schools and trainers.

Conclusion: It is believed that not only professionals should take care of children, but that children's mutual concern and support can lead to the formation of a compassionate community.

ID: 220
Abstract Type: Poster

Topics: Networks and compassionate communities, Care in humanitarian contexts

Keywords: Needs and Barriers, Home-based End of Life Care, Health care delivery, Palliative Care

Perspectives on Needs and Barriers to Home-Based End-of-Life Care Delivery in Thailand

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Background: Providing end-of-life care at home is crucial to achieving a peaceful death for dying patients. Understanding the needs and barriers related to providing such care is essential toward improving the quality of care and facilitating care delivery at the home setting.

Objectives: This study aimed to describe the needs and barriers of end-of-life care delivered at the home setting in the Thai context.

Design: A qualitative descriptive study was conducted.

Methods: 17 patient and 43 family caregiver informants were purposively selected from four regions of Thailand. The research instruments included a demographic data form and interview guides. In-depth interviews were used for data collection, and content analysis was applied.

Results: The identified domains of end-of-life care delivered at the home setting were: 1) physical care, 2) medication care, 3) psychological care, 4) transferal to the emergency department due to uncontrollable symptoms at the home setting, and 5) comfort care based on cultural beliefs. The two main barriers to this type of care were, 1) a lack of self-confidence in delivering care to the dying loved one, and 2) financial constraints. Patients and their caregivers reported several needs related to home-based care, namely: 1) financial support, 2) ability to deliver the best quality of care, 3) convenient and fast-track services, 4) 24-hour consultation, 5) continuity of care, 6) information related to diseases and treatment plans, 7) caregiver support, and 8) support related to medical equipment and supplies.

Conclusions: Our results emphasize the importance of consolidating the continuity of care from hospital to home and enhancing bereavement-care services. Additionally, the implementation of programs that aim to enhance the capacities of family caregivers to provide care for end-of-life patients at home is strongly recommended. Finally, the provision of essential social and economic support for the families of such patients is also a must.

ID: 221
Abstract Type: Poster

Topics: Relationships and connection, Research methods

Keywords: COPD, hope, palliative, dyads, relationships

Exploring the hope experience and quality of life among dyads of people and their informal caregivers living with chronic obstructive pulmonary disease in Switzerland: First results from qualitative data analysis

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Background: COPD is the global third leading cause of death, with prolonged care needs over time posing a multifaceted public health (PH) challenge. Characterized by its widespread prevalence, significant morbidity and mortality, substantial healthcare costs, this disease significantly burdens patients,through a worsening symptom profile,diminishing quality of life(QoL) and impacting hope. Informal caregivers(ICs), who play a crucial role in supporting patients are equally impacted.This underscores the need to address both patients' and ICs needs for a comprehensive disease management approach.Hope and QoL are understudied in this population, especially among ICs, highlighting the importance of recognizing and addressing these aspects in a holistic COPD management strategy with concomitant implications for PH.

Objectives: The dynamic experience of hope and the relationship between hope and QoL in dyads of people living with advanced COPD and their ICs are explored over time.

Design: A longitudinal multicenter mixed-methods study with a convergent design.In this abstract we highlight the qualitative results.

Methods: Qualitative data was collected from dyads of advanced COPD patients and their ICs at three hospitals in French-speaking and Italian-speaking Switzerland,at two different time points.

Results: Preliminary findings highlight that deterioration in health status,physical decline and symptom burden are pivotal factors which shift the perception of hope and QoL over time in dyads of COPD patients and ICs.Emotional and practical support provided by family members,friends and healthcare professionals emerges as a key element in maintaining and enhancing hope.Additionally, resilient personality traits such as optimism and stoicism can help dyads with the ability to cope with the illness and maintain a positive outlook for the future.From a public health perspective,understanding the importance of these factors can inform the development of interventions and policies aimed at improving the well-being and strengthening communities to provide care and support and potentially reduce overall healthcare costs.

Conclusion: This study provides an important perspective on the dynamics of hope in dyads of people living with COPD and their ICs over time. Understanding sources of hope may inform targeted interventions and support strategies to improve QoL.This knowledge emphasizes the crucial role of dyads relationships in care planning and social support.

ID: 223
Abstract Type: Poster

Topics: Research methods

Keywords: EQ-5D-5L, ICECAP-SCM, IPOS, patient-reported outcome measures, psychometric validation

Validity of the German ICECAP-SCM capability wellbeing measure assessed in specialized palliative care wards in Austria

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Background: Patient-reported outcome measures (PROMs) with robust psychometric properties serve as valuable tools for informing health and care decision-making. In cost-utility analyses, health outcomes are typically measured using health-related quality of life instruments. However, the scope of holistic palliative and end-of-life care extends beyond health, including additional value dimensions. The ICECAP-Supportive Care Measure (ICECAP-SCM) aims to address this need, representing a recently developed capability-wellbeing measure with seven-attributes tailored for economic evaluations within palliative and end-of-life care settings.

Objectives: This study aimed to assess the psychometric properties of the German ICECAP-SCM.

Design: A multicenter cohort study of patients with palliative care needs admitted to specialized palliative care wards in 12 Austrian hospitals between October 2021 and April 2023.

Methods: In addition to the ICECAP-SCM, we assessed health-related quality of life (EQ-5D-5L) and the Integrated Palliative Care Outcome Scale (IPOS), a PROM to assess symptoms and other concerns of palliative care patients. We assessed the convergent validity, discriminative validity, structural validity, and responsiveness of the ICECAP-SCM.

Results: 228 patients completed all three PROMs and were included in the analysis. Correlation (r) between the ICECAP-SCM summary scores and the IPOS summary scores or the EQ-5D-5L summary scores was similar, -0.32 and -0.27, respectively. The IPOS summary scores and EQ-5D-5L summary scores showed significantly stronger correlation (r = 0.48). Two strong and eleven moderate correlations were found between ICECAP-SCM attributes and items from other measures. The ICECAP-SCM *Emotional Suffering* attribute correlated strongly with the IPOS *Depression* item and the EQ-5D-5L *Anxiety/Depression* item. Other validity tests are currently ongoing.

Conclusion: This study provides initial evidence of the validity of the ICECAP-SCM capability-wellbeing measure in specialized palliative care wards in the hospital context. Overall, the results suggest that the constructs of IPOS and EQ-5D-5L are more closely related than those of the IPOS and ICECAP-SCM. This is likely to lead to potentially important conflicts between purposes such as clinical actionability, quality assurance versus usefulness for broader value assessment.

Funding: The Austrian Science Fund (FWF) Lise-Meitner program (M2795)

ID: 226
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving

Keywords: cardiovascular diseases; place of death; palliative care; trends; public health;

Trends in the place of death for people with cardiovascular diseases in Sweden 2013-2019

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Background: Cardiovascular diseases (CVD) are the most common cause of death globally, as in Sweden, often with high symptom burden. Despite this, palliative care is underutilized. A marker for the quality of end-of-life palliative care in a country is globally accepted to be death in the preferred place, considered by many to be their own home. This quality indicator could be indirectly affected by emerging policies that shape health care services.

Aim: The aim was to examine trends in place of death among adults with CVD, after the first national guidelines for palliative care were launched 2012-2013 in Sweden, and examine potential associations to individual, clinical, geographic and socioeconomic factors.

Methods: Population-level longitudinal trend study based on registry data of adults deceased due to CVD (n=209 671) between 2013 and 19. Logistic regression, with place of death as dependent variable, and interaction analysis was applied to explore associated factors and variation in place of death.

Results: Overall, the predominant place of death was nursing home (39,1%) and hospital (37,6%), followed by home (22,0%). From 2013 - 2019 hospital deaths decreased by 3,0% and home deaths increased by 2,8%. This trend was seen in all six regions, most pronounced in the Southern. If living at home, the likelihood of dying in hospital versus home decreased from 2016 to 2019 (OR 0.82). Over the study period, an increase in home deaths was seen in all individual CVD types (+1.5-5.7%), and a decrease in hospital deaths (-2.0-8.5%) in all but cerebrovascular disease (+1.3%). Significant factors associated with dying in hospital versus home for home dwellers were having the ICD-code for palliative care (OR 2.21), potential palliative care needs (OR 2.19) and age > 80 (OR 1.87). Only 2.2% died in a specialised palliative care setting and 2.7% had the ICD-code for palliative care, whereas 94.2% were estimated to have potential palliative care needs.

Conclusion: From 2013-2019 people dying due to CVD in Sweden do so to a slightly less degree at hospital and more often in their own home, independently of health care region and (most) CVD types. Yet only a minority (22%) die at the presumed preferred place of death; one's own home. A plausible reason could be that only 2.2% of the total CVD population receive specialised palliative care at death, despite 94% having potential palliative care needs. This warrant attention to policy and clinical practice as well as further studies.

ID: 227

Abstract Type: Oral presentation

Topics: Relationships and connection, Social and structural determinants of death dying and grieving

Keywords: Assisted dying, End of life, Indigenous, Maori Palliative Care

"I don't know what options there are": Indigenous families' experiences with cancer and assisted dying in Aotearoa New Zealand

Tess Huia Moeke-Maxwell, Jackie Robinson, Lisa Williams, Jeanette Scurr, Tau Huirama

University of Auckland

Background: The End of Life Choices Act (2019) provides a new end-of-life option for New Zealanders living with incurable illness. Without appropriate information and navigational support to guide and prepare whānau (Māori families) and their communities the Act can create further inequities for Māori. The Ministry of Health's first year review revealed small numbers of Māori are using assisted dying services including those with incurable cancer.

Objectives: Our aim was to explore how Māori whānau accessed and engaged with assisted dying services and the impact the Act's prohibition (health professionals' inability to initiate conversations about assisted dying) had on whānau who wanted an assisted death.

Design: Qualitative Kaupapa Māori Research methods were used to interview forty whānau about their experiences of using, or wanting to use, assisted dying services. Findings are being transferred into resources using Arts Based Knowledge Translation methods.

Methods: Participants were recruited from across New Zealand using Māori networks. Twenty support workers (assisted dying clinicians, rongoā practitioners, spiritual leaders, and health professionals) were interviewed about their experiences of caring for people who received an assisted death. An inductive thematic analysis was used to analyse the data.

Findings: Indigenous communities are uniformed about assisted dying. Most adults who had an assisted death, or who wanted to hasten death, had cancer. Preference for assisted dying was influenced by observing whānau members, who had cancer, dying in pain. Participants wanted to avoid an undignified death. Many were unaware of the prohibition placed on health professionals, the eligibility criteria and what the process and procedure involved. Individuals who knew the ACT was legislated used their mana motuhake (autonomy and independence) to seek information. It was often difficult to discuss assisted dying with whānau and friends. Bereaved whānau experienced a sense of accomplishment in helping to release the person from intolerable suffering; this supported their grieving processes.

Conclusion: Māori use assisted dying services supported by their whānau however, their communities are unaware of the ACT. Culturally appropriate and accessible information is required to ensure access to assisted dying services is equitable. Whānau and their communities need support to help them discuss assisted dying to support them to make an informed decision.

ID: 228

Abstract Type: Oral presentation

Topics: Relationships and connection, The value of death

Keywords: End of Life, Grief, Indigenous, Maori, Palliative Care

Indigenous 'dying' gap: An auto-ethnographic reflection of one urban Indigenous family's experience of caring for their dying mother

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Background: Culture and spirituality have been identified in previous research studies as important cornerstones of Indigenous palliative care. Māori families want to fulfil their cultural obligations to care for rural Indigenous elders. However, some New Zealand families have lost tribal caregiving knowledge and funeral customs. Can mobile, global, urban Indigenous families bridge the cultural caregiving gap?

Objectives: The aim was to explore our Indigenous urban family's experience of caring for our rural mother who died in a New Zealand aged residential care hospital after a six week illness. We wanted to explore how whānau (family), and people who return home, fulfil their cultural obligations to care for dying elders. We asked, 'can urbanised, mobile, Indigenous whānau adapt their customs to care for older people at the end of life and how does this impact bereavement?'

Design: We used auto-ethnographic methods and Kaupapa Māori analysis to explore our urban Māori family's experience of caring for our older Indigenous mother before and after she died in an urban aged residential care hospital. Following her death, we explored the reclamation of Māori death customs, caregiving roles and bereavement by conducting a reflexive analysis. We drew from pārākau (stories) shared by family members before, during and after her death, and our written social media communications, to review our collective experiences.

Findings: Our whānau lacked in-depth knowledge of traditional caregiving and funeral customs due to being first generation born mobile, urban Māori. We adapted by drawing from tribal values instilled in us by our mother; we used our collective cultural knowledge to become powerful caregiving allies and communication conduits. Where there were questions, we sought answers from caring health care professionals. Cultural and spiritual support came from experts outside our whānau. Together, we ensured our mother had good palliative care within the health care system. Our unified aroha (love, care, and compassion) supported our mother to die peacefully, with culturally appropriate funeral customs and spiritual care. The experience strengthened our grieving process.

Conclusion: Urbanised Indigenous families can adapt their ancient cultural knowledge to care for dying Indigenous elders who require specific cultural and spiritual support. Cultural customs nurture and protect dying elders, and the reclamation of cultural customs help strengthen families to grieve effectively.

ID: 229
Abstract Type: Oral presentation

Topics: Research methods

Keywords: End-of-life homecare, family caregivers, participatory action research, nurse-led intervention, co-design and community engagement

Methodology to co-produce an intervention to support family caregivers caring for loved ones at their end of life (CEOL-CARE)

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Background: In Switzerland people's often wish to die at home. However, caring for a loved one at the end-of-life at home is challenging for family caregivers. Initiatives to support them exist but they often fail to meet their needs. Yet, lack of support hinders family caregivers' physical and psychological health, as well as their grieving process. Unplanned emergency hospitalizations are also increased consequently. The project aims to co-design a nurse-led intervention for family caregivers accompanying a person at the end of life at home in order to increase their confidence and capacities.

Objectives: To present the methodology we used to co-design this intervention and the indicators we used to assess the effectiveness of this participatory action research (PAR).

Design: PAR is an approach that actively engages stakeholders and caregivers throughout the research process in order to bridge scientific and experiential knowledge.

Methods: The research team include a family caregiver, a general practitioner, 4 nurses, 4 psychologists and a sociologist. The project consists in 4 steps: 1) literature review to identify interventions to support family caregivers, 2) interviews with professionals and family caregivers concerned by end-of-life homecare, and a map of services available on the territory, 3) participants' feedback of results and prioritization of needs, 4) co-production of an intervention.

Results: Steps 1 to 3 allowed us to identify family caregivers' needs for end-of-life homecare and to highlight that the current services are poorly accessible and coordinated. Thanks to meetings, family caregivers report increased confidence in their abilities, creation of meaningful relationships among and between family and professional caregivers and better service know-how.

Step 4 involves the creation of three working groups mixing family caregivers, associations, and professionals to improve 1) assessment of family caregivers' needs during end-of-life homecare, 2) response to those needs, and 3) partnership between professionals and family caregivers. An evaluation of how the process is perceived by participants and could allow us to reach the goals of CEOL-CARE is also ongoing.

Conclusion: The main outcome of co-designing an intervention that meets family caregivers' priorities and considers the local context is about to be met. The community's engagement and the initial results encourage us to pursue this project, which could serve as a basis for national deployment.

ID: 230
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving

Keywords: Family caregivers, carers, population

Demographic profile of end of life family caregivers in the UK: an observational study

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Background: Family and friends who provide unpaid care (family carers) play a vital role in supporting people towards the end of life. Family caregiving at the end of life is associated with a range of negative impacts on health and wellbeing, and supporting end of life family carers has been recognised as a national priority in the UK. Despite this, there are no population level estimates of the number of end of life (EOL) family carers in the UK and little is known about the demographic profile of this group.

Aim: The aim of this study was to estimate the number of EOL family carers in the UK and describe demographic characteristics of this group.

Design: Secondary analysis of observational data from the UK Household Longitudinal Survey (UKHLS).

Methods: UKHLS collects health and social data annually from around 40,000 households in the UK. We used data from all waves from 2009 - 2020 (inclusive). EOL family carers were defined as participants aged > 16 years, who self-identified as a carer for someone (>16 years) in their household, where the care dependent died before the household's next annual interview. We also used the "UK population estimates" dataset from the Office for National Statistics to provide national prevalence data.

Results: The number of EOL carers in the UK varied between approximately 135,000 and 180,000 per year. On average, approximately 4% of household carers were EOL carers each year and 16% of household carers would become an EOL carer at some point. We did not find major differences between the distribution of EOL carers and the general population regarding country of residency (England, Scotland, Wales, Northern Ireland) or ethnicity. However, we did find an older population among EOL carers, with 60% aged between 50 to 79 years compared with 42% in the general population. We found an over-representation of females (57% vs 52% in the general population) and individuals with lower education levels (44% had left school at the minimum age vs 26% in the general population).

Conclusions: This is the first study to use representative population data to establish the number of EOL family carers in the UK. We estimate that over 130,00 people are providing unpaid EOL care each year. EOL carers are more likely to be older, female and have lower educational levels. The findings contribute to increased understanding of the needs of EOL family carers in the UK and suggest a need for targeted interventions to address their specific needs.

ID: 231
Abstract Type: Poster

Topics: Policy and advocacy, Death and grief literacy

Keywords: advance care planning, advance directives, end of life care, medical proxy, pallaitive care

Advance Care Planning: Why are patients interested?

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Background: Advance care planning (ACP) is a term introduced in the literature in the 1990s describing a range of interventions involving discussions between patients, families and health care providers about future medical care. The process often leads to decisions about life-sustaining therapies, resuscitation and nomination of a medical proxy. ACP has improved end of life care due to the shared decision making process and patient-centred care. The aim of this study was to determine factors that influence patients to engage in advance care planning.

Methods: A literature review was conducted in a systematic manner over a 12 month period. A literature search was conducted on three databases: PubMED, CINAHL and EBSCO using key words "advance directives", "advance planning", "living will", "medical proxy", "durable power of attorney", "terminal illness", "life limiting illness", "palliative care", "end of life". The search yielded 2,005,965 papers. The search was limited to English language, adult subjects (18 years and above) and years of publication from 1975 to 2018. 437 abstracts were reviewed. 19 met the inclusion criteria for this review. 15 had used qualitative methods and 4 quantitative methods. After critical appraisal 14 studies were selected for review.

Results: Data was analysed using a thematic approach. Emerging themes were family involvement, attitudes towards death, spirituality, age, race, gender, past experiences of illness, prognosis, personal dignity and level of education. Patients who were likely to engage in ACP were those with strong family involvement, those who were ready to face their mortality, were religious, female and older adults.

Conclusion: ACP is a useful tool in end of life planning though it is not widely used. Research in this area also remains limited. Some areas of future research include primary studies on the influence of culture on ACP, existing policies on ACP as well as knowledge and attitudes of healthcare providers.

Lessons learnt: Many cultures are family oriented, therefore patients prefer to have discussions about their wishes as opposed to having written advance directives. ACP should therefore focus on the process of discussion and understanding wishes rather than documentation of wishes.

ID: 232
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Educational approaches

Keywords: Indigenous communities, palliative care education, community-based, cultural safety, equity

Walking alongside Indigenous Peoples who are seriously ill: Education for community caregivers

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Background: Indigenous communities view dying as a social and community event where caregiving is provided by family and community. Family and community networks are important to Indigenous people, and kinship is integral to their culture. To meet the educational needs of community caregivers, a partnership was established with Indigenous communities in Canada to develop the “Walking Alongside Indigenous Peoples Who Are Seriously Ill: Education for Community Caregivers” curriculum.

Objectives: This curriculum aims to enhance the capacity of health and social care providers in Indigenous communities to provide community-based education and support to families and community members caring for loved ones with life-limiting illnesses. This curriculum helps improve the knowledge and skills of family and community care providers by providing education and resources on bedside care and supporting people’s social, cultural, and spiritual needs.

Design: The curriculum is based on clinical best practices and follows a “train the trainer” format. It is rooted in the Indigenous Wellness Framework, which incorporates community’s experiences, culture, values, and beliefs into the education. An advisory committee reviewed the curriculum through the development process to ensure that it was culturally relevant and met the needs of community caregivers.

Results: This web-based curriculum includes a manual with over 90 supporting resources. It focuses on spiritual, emotional, mental, and physical wellness. It provides guidance on developing a care plan, making your wishes known, the palliative approach to care and the last days and hours of living. The curriculum has been introduced to over 200 Indigenous communities across seven provinces in Canada through community-based workshops.

Conclusion: This education provides a Canadian example of implementing a public health approach to palliative care education in an Indigenous context. The education outlines a community engagement process in developing and delivering community-based education. Lastly, the education provides examples of community-developed resources and discusses the potential global application to other contexts.

ID: 233
Abstract Type: Oral presentation

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: Death literacy, Philosophical Practice, Care Ethics, Compassionate communities, Pragmatics of understanding

“To philosophize means learning to die” – developing death literacy in communities of philosophical and palliative care practice

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Background: Dealing with existential questions in the face of death is a constitutive part of palliative care. To make space for the topic of death in everyday life conversations, we can meanwhile rely on a repertoire of concrete practices: e.g. last aid courses, death cafés, and practices from spiritual care. However, Philosophical practices are not considered—which marks the beginning of our research interest. Philosophical practice is a non-elitist approach to doing philosophy and enables people—in the Socratic tradition—to reflect on their (existential) everyday life experiences in a philosophical way. In our ongoing research project “Philosophical Practice in Palliative Care and

Hospice Work", we seek to close this gap by practically investigating the opportunities and limits of philosophical practice for the development of death literacy.

Design: In this contribution we will a) briefly introduce philosophical practice, b) focus on the evaluation and analysis of a series of philosophical group events in the palliative care context and present (interim) results, c) draw conclusions with regard to the concept and dimensions of death literacy.

Methods: In the empirical part of this contribution, we conduct a qualitative document analysis of protocols and personal notes provided by the involved philosophical practitioners, complemented by group discussion with them and participants' feedback. We combine this analysis with philosophical analysis, interpreting the results regarding implications for the concept and dimensions of "death literacy" itself.

Results: Philosophical practice can make important contributions to developing death literacy according to its known dimensions. Moreover, by deepening and critically questioning what is self-evident within the social and personal life-philosophies we pursue, philosophical practice adds to the development of the concept of "death literacy" itself.

Practical conclusions: We give insight into how philosophical practice can be applied in end-of-life care in communities and everyday life.

Funding: This research is funded by the Austrian Science Fund (FWF) P 35627-G.

ID: 234

Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving

Keywords: palliative care; inequities; deprivation; rurality; service use

The impact of area deprivation on access to and utilization of health services in the last year of life: a retrospective population based cohort study

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Background: The healthcare needs of people living in areas of high deprivation are complicated by the cumulative effect of the socio demographic factors known to impact on health outcomes, such as income, housing and education. Of note, for people living in more deprived areas, life expectancy is shorter and the onset of chronic disease and multi morbidity occurs much earlier. While the relationship between area deprivation and access to palliative care is becoming more widely researched, the vast majority of studies to date have focused on referrals to specialist palliative care services. This is problematic given the dominant model of generalist-specialist palliative care in high income countries which assumes that most people will have a level of need that can be managed by non-specialist palliative care services.

Objectives: To identify associations between area deprivation and the use of generalist and specialist palliative care services in the last year of life.

Design: A retrospective population-based cohort study of people aged over 18 years who died between January 2015 and December 2020 within one geographical area of Aotearoa New Zealand.

Methods: Using the National Health Identifier unique to each individual, deaths were matched to generalist and specialist palliative care service data. Deprivation was measured using the New Zealand Index of Multiple Deprivation. ICD10 codes were used to identify primary and secondary diagnoses. Logistic regression analysis was undertaken to identify predictors of service use in the last year of life.

Results: A significant association was found between area deprivation and health service use in the last year of life. Of note, people living in rural areas of deprivation were significantly less likely to receive a hospital ($p=3.11E-06$) or inpatient hospice admission ($p=0.000$). They were also less likely to have contact with their general practitioner ($p=0.007$) or experience a specialist outpatient clinic appointment ($p=0.0016$).

Conclusions: This study has revealed inequities in health service use across generalist and specialist palliative care services for people living in areas of deprivation. Of note, findings have highlighted how rurality amplifies inequities in access to appropriate palliative care. Further research is needed to better understand the consequences of these apparent inequities.

ID: 235

Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving

Keywords: Health services accessibility; Home care; Paediatrics; Palliative care; Palliative medicine; Public health; Social determinants of health

Place of Death Among Children: a population-based study from Sweden

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Background: Every child with a life-threatening or life-limiting illness, along with their families, has the right to receive palliative care. In Sweden, the integration of palliative care into the welfare system is influenced by decentralized healthcare structures, resulting in regional variations in the organization, expertise, and resources of palliative care.

Design: Data were obtained from national register holders. Underlying causes of death were categorized based on diagnosis codes according to ICD-10 for perinatal conditions, cancer and neuromuscular conditions.

Objectives: To contribute to the development of paediatric palliative care by examining its prerequisites at the population level concerning the location of children's (0–17 years) deaths.

Methods: The research spanned 2013–19, employing descriptive statistics to assess the distribution and variations in the location of death. Multivariable binary logistic regression analyses were conducted to ascertain the impact of associated factors.

Results: Most children died in hospitals (74.7%). Sex and birthplace showed no significant differences in home deaths. There were regional variations in home deaths, with the highest percentage in the Northern region (23.3%). Deaths due to malignancies (39.0%) had a likelihood of occurring at home, for perinatal diagnoses— the incidence of home deaths was relatively low (1.5%).

Conclusion: The scarcity of paediatric deaths has earlier been shown to result in limited home care for children and potential deficiencies in paediatric palliative care infrastructure. Given Sweden's vast geography, sparse population, and the growing role of eHealth, the study discusses the potential of establishing national or regional consulting teams to ensure equitable access to specialised palliative care for all children, irrespective of their residence. Most children die in hospitals, this does not necessarily reflect the preferences of the child or family.

ID: 236

Abstract Type: Workshop

Topics: Networks and compassionate communities

Keywords: Compassionate Workplaces; Compassionate Communities; Workplace interventions

Compassionate Workplaces in Europe: sharing experiences and resources

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Target Audience: This workshop is for people who are interested or involved in creating more compassionate workplaces relating to death, dying, loss and care.

Learning Objectives: Participants will:

- have explored different potential approaches to making workplaces more compassionate communities in relation to death, dying, loss and care;
- have thought about the strengths and weaknesses of different approaches;
- be more aware of some of the real-world challenges intrinsic to encouraging more compassionate workplaces;
- have shared and learned about existing relevant workplace resources to support employees faced with serious illness, death and bereavement.

Structure of the Workshop: Most people will experience bereavement, ill health or caring responsibilities at some point during their professional life. Such experiences affect people's health and wellbeing, but also the work environment in terms of productivity and safety. Different aspects of workplace organisation can influence the job demands and resources of jobs and work environments such that employees can feel unsupported when coping with EoL experiences. Workplaces can play an important role in providing flexibility, information, understanding and social support to employees going through difficult times.

The workshop draws on one research-based and one practice-based case study across five European countries where projects are underway to encourage more compassionate workplaces: the EU-CoWork project and the Scottish Bereavement-Friendly Workplaces Toolkit and Bereavement Charter Mark.

1. EU-CoWork is co-creatively developing tailored Compassionate Workplace Programs in 12 workplaces across 4 European countries (BE, SE, AT and GR), employing developmental evaluation and an international mixed methods process and impact evaluation.
2. In Scotland, work is underway to encourage employers to create more 'bereavement-friendly' workplaces through use of the Bereavement Charter Mark for Employers and the Scottish Bereavement-Friendly workplaces toolkit.

Brief presentations on each project will outline their aims, approaches, challenges and learnings. Small group discussions will give delegates the opportunity to share their own experiences in this area; view and discuss some of the resources used in the case study areas; and think about whether elements from these projects might be of use in their own context. There will also be opportunities for questions to speakers and plenary discussion of key issues.

ID: 237
Abstract Type: Poster

Topics: Research methods

Keywords: equity, specialist palliative care

How is equity of care measured by specialist palliative care services? Results of a scoping review

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Background: Despite health equity being a focus of many organizations, including the World Health Organization, equity of palliative care outcomes are not routinely measured by many specialist palliative care services.

Objectives: This study aimed to identify measures used to assess equity in palliative care service delivery, in order to help specialist palliative care services address measurement gaps and address inequities in their service provision.

Design: Scoping Review

Methods: The following databases were searched to identify articles up to May 2023: Medline (Ovid), Embase (Ovid), CINAHL (EBSCOhost), and Cochrane Central Register of Controlled Trials (Ovid). Equity factors were assessed based on "PROGRESS-Plus": place of residence, race/ethnicity/culture/language, occupation, gender/sex, religion, education, socioeconomic status, and social capital, Plus age, disability, and sexual orientation. We included disease type (e.g., cancer or non-cancer) in the "plus" factors. Abstract, full-text screening and data extraction were completed by two independent reviewers, with conflicts resolved by a third reviewer, following JBI scoping review methodology.

Results: 14,964 records were screened for inclusion; 1451 full texts were reviewed, of which 284 were included in the final analysis. Approximately half of the included texts were from the USA. Place of death (11%), patient symptoms (10%) and costs of care/health resource use (9%) were the three most common palliative outcomes assessed for inequities. Gender/sex (18%), age (17%), disease type (13%) and ethnicity (13%) were the most common equity factors assessed. Analysis of health administrative data was the most frequently reported measurement method for both palliative outcomes (32%) and equity (32%). Notably, many equity factors including sexual orientation, language spoken, disability,

homelessness and substance use disorder were rarely measured.

Conclusion: Important gaps exist in how equity of care is being measured by specialist palliative care services. Findings from this scoping review provide an opportunity to develop new measures and embed existing equity measures into the indicators that will shape palliative care delivery in the coming years.

ID: 238
Abstract Type: Oral presentation

Topics: Death and grief literacy, Educational approaches

Keywords: Grief literacy, collaboration, compassionate communities, education

Creating Compassionate Communities after loss: Results from the evaluation of an international grief literacy program

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Background: The bereavement companion program was a pragmatic response to the need for bereavement support in Kerala, India, during the covid 19 pandemic. The program was developed as an international collaboration with a core interdisciplinary team and then with bereaved people in Kerala who volunteered to support the design of the program. Focus groups were run via Zoom with translation, and this process supported the initial design of the program and then the pilot program. Since the online pilot program in 2021, 363 people have participated online (nine programs) and in person (five programs) in India, Bangladesh, Thailand, Philippines and Australia. A supporting manual and other resources have been developed and translated into multiple languages. This presentation provides an overview of the outcomes of a 5-country evaluation in 2023, the lessons learnt and the benefits of international collaborations.

Objectives: To examine the effectiveness of a community grief literacy program. It was proposed that participants would gain knowledge and confidence from the program and that the program would provide a safe space for community members to reflect on their own grief experiences and the experiences of others, equipping them to be ‘companions’ in grief to friends, family, and neighbours.

Design: Evaluation of a grief literacy program for community members.

Methods: All program participants across 5 countries in 2023 were invited via direct link or QR-Code to participate in an online survey with both Likert style and open-ended questions. The survey was confidential, and participation was voluntary. The survey had 25 questions, including demographics, questions about confidence and knowledge and the program goals.

Results: A total of 169 participants completed the program in 2023; 107 (69 female, 33 male) from 5 countries completed the evaluation survey (63% response rate). Paired sample t-tests revealed a significant difference in self-reported confidence and grief-related knowledge on self-reported pre-post scores. The effect size was large (Cohen’s d). Over 70-80% of participants reported the workshop provided a space to reflect on their own grief, it helped normalise grief support and 83% reported it improved their grief literacy.

Conclusion: The grief companion program improves knowledge and builds confidence in response to grief in the community. The evaluation will be used for continual improvement and to share the program in other countries and regions.

ID: 239
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Networks and compassionate communities

Keywords: caregiving, structural inequities, healthcare access, cancer, support networks

Understanding caregiving for people living with cancer alongside homelessness and poverty at the end-of-life

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University of Victoria, Canada

Background: Cancer is one of the leading causes of death worldwide. Caregivers (e.g., friends, families, neighbors) are essential sources of support for people with cancer across the continuum of care and become even more important towards the end-of-life. Research has shown how the social and structural determinants of health shape access to healthcare at the end-of-life, but little is known about how these determinants shape caregiving especially in contexts of poverty and homelessness.

Objective: The objective of this multi-site, Canadian study (2021-2025) is to provide a detailed description of caregiving in settings of homelessness and poverty to: (1) map who the caregivers are; (2) describe the care tasks that they do; and (3) describe contexts that shape caregivers' experiences.

Design: This study employed an ethnographic research design informed by critical theoretical perspectives of social justice and equity. Interpretive thematic analysis was used to develop detailed contextualized accounts of caregiver experiences.

Method: We completed over 200 hours of participant observation and in-depth interviews with three groups of caregivers: (1) bio-legal family; (2) friends, neighbors, and 'chosen' family; and (3) community service providers. This was supplemented by in-depth interviews with key informants in the healthcare and social sectors (e.g., housing and shelters, harm reduction facilities).

Results: Preliminary data show how social and structural inequities shaped caregiving for all groups of caregivers in contexts of poverty and homelessness. Estrangement and complex relationships with bio-legal family meant that 'traditional' family caregivers were not always able or available for care. Support networks consisting of friends, neighbors, and workers often existed but their role at the end-of-life was not always clearly defined or understood by health and palliative care systems. Alongside traditional caregiving tasks, caregivers worked to meet social and structural determinants of health needs (e.g., food security, eviction prevention).

Conclusions: There is a need to better understand and enable the important, yet often invisible caregiving work in contexts of poverty and homelessness. Interdisciplinary and intersectoral collaboration alongside practical strategies to identify, engage, and support networks of care outside 'traditional' family models are needed to strengthen the quality of life for people with cancer at the end-of-life.

ID: 241
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving

Keywords: Pediatric palliative care, life-limiting illness, prevalence, cross-sectional study

Determining palliative care need in pediatric patients cared for by home health care

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Background: In Switzerland, an estimated 5000 children need palliative care. Prevalence or incidence on children and young adults in need of palliative care or mortality rates are difficult to obtain in Switzerland. A major obstacle to such data is the federal system of Switzerland, where each canton has its own healthcare system. It is assumed that only about 10% of the children and young adults needing pediatric palliative care (PPC) are currently receiving this specialized service in Switzerland.

Objective: The aim of this study was to determine the number of children with a life-limiting disease meeting the criteria for PPC who lived at home and were cared for by home healthcare in one of the German speaking cantons of Switzerland. The characteristics of these children and their families were described.

Design: A cross-sectional, retrospective study was conducted.

Methods: With the Start-Impact questionnaire, the PPC needs was determined of home-bound children cared for by home healthcare organisations in one of the largest German speaking cantons of Switzerland. This questionnaire comprises a rapid test and a main part. The rapid test includes seven items. By ticking each item, a total score of 4 can be obtained. If that's the case, the main part has to be completed, which comprises seven areas with several items each. These items allow for clearly identifying the specific PPC need. The data was collected from the electronic documentation system of a total of five home healthcare organisations in this canton between January and June 2021.

Results: A total of N=108 children were identified who passed the rapid test. Most children

(78%) had a low need for specialized PPC, 14% had a moderate need, and 8% had a high need. In the last group, 56% of the children did not have access to specialized PPC. Most of the children (91%) with moderate need of specialized PPC did not have access to it. For caregivers, the burden was high.

Conclusion: The burden of illness and care for children with specialized PPC need and their families is high. Access to PPC is inadequate. Care and treatment gaps in various areas exist. Establishment of a specialized PPC team is recommended. Further research is needed.

ID: 242
Abstract Type: Workshop

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: grief literacy, public festival, community engagement, Canada

Good Grief, Nova Scotia! A workshop about building a successful grief festival

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There is an expression that community organizers flirt with in hopes it will be true: *If you build it, they will come*. We had this experience – both the hope and then the success – when we built and delivered *Good Grief, Nova Scotia!* (GGNS), a festival to grow grief literacy across an entire Canadian province in 2023.

Nova Scotia is home to 1 million people, many living in rural and semi-urban communities. GGNS was the first festival in Canada to bring the topic of grief into public view. Across 8 days, we hosted 36 events both virtually and in person. Advertising included social media, posters, radio and television engagement. Activities embraced the tenets of grief literacy in the following ways:

- They were tailored to different ages, communities, genders, sexualities, incomes, and geographic locations. Many events were on-line. Most events were physically accessible, and at least one had sign language interpretation.

- They included a range of griefs. For example, widows grieving their spouses; pet owner grieving their companions; newcomers reflecting on what they had to leave behind in their home countries.

- They were in public places: For example, the main library in the provincial capital hosted a display of memorial tattoo photographs; people talked about their grief over restaurant meals; folks gathered in a park to learn about death doulas; people joined online to discuss estate planning; grievers missing their deceased pets went on hikes together.

- They were hosted by individuals, community organizations, health care institutions, faith-based organizations, and research teams. Most events were free; some had ‘pay what you can’ entry fees.

Target Audience

This workshop is for anyone who would like to contribute to growing grief literacy in their networks and communities.

Learning Objectives

- To learn about building a successful grief literacy festival using crowd-sourced content;
- To share ideas for tailoring grief literacy activities to participants’ communities;
- To discuss meaningful evaluation metrics, asking: What is a marker of success for grief literacy?

Structure of the Workshop (90 min)

- Introductions (10 min)
- Presentation about *Good Grief, Nova Scotia!* (15 min)
- Break-out groups to brainstorm and discuss the following:

- Ideas, challenges, and solutions for events and activities (20 min with reporting back to larger group)
- Ideas for evaluation (20 min with reporting back to larger group)

- Large group discussion (20 min)
- Concluding remarks (5 min)

ID: 243
Abstract Type: Oral presentation

Topics: The value of death, Death and grief literacy

Keywords: home funeral, community, family led, deathcare, grief

The how and why of home funerals

Rebecca Jane Lyons

Solace End of Life Services, Australia

Background: There is a growing movement toward citizen led end of life, death and bereavement care. This includes the reclaiming of personal rites and rituals alongside complimentary palliative care and funeral providers. A number of social changes are influencing this change in Australia, including the need to develop models in under-served communities and seeing this care as a social justice issue not just a medical one.

Objectives: Many of us across end of life care and funeral care. Understand the value of home funeral. The objective of this presentation is to show people, through pictures and stories, how home funerals work and the difference that they can make to the grief and bereavement of those who live on.

Design: In this multi-media presentation I will take people on a photographic journey of a number of deaths. Each death was different; suicide, sudden and traumatic death, nursed dying at home, old age – they all come with their stories and lessons and ultimately, they show people what is possible for a family to do when a person is dying.

Methods: A family conducted different versions of home funerals, incorporating their extended family and community. Those deaths were documented in pictures and are told from an ethnographic perspective.

Results: Through the experience of a number of deaths, this presentation demonstrates the very real benefits to the bereaved, that can be gained from people caring for their dead. By sharing personal experiences and reflections, this presentation works to skill people in increased death literacy and expand peoples knowledge of what is possible in community and family based approaches to end of life.

Conclusion: This presentation explores the impact of death education and advocacy in Australia and provides an argument against the silo-ing of care at end of life. It argues that continuous care can make these last acts of service have the potential to fundamentally change the grief and bereavement experience for people and their families and communities.

ID: 244
Abstract Type: Poster

Topics: Care in humanitarian contexts

Keywords: end-of-life, death, home care, visiting nurses, advance care planning

Challenging issues perceived by Japanese visiting nurses in implementing advance care planning and realizing death at home

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Objective: Since Japan has the world's longest life expectancy, end-of-life care outside of hospitals is being promoted, and advance care planning (ACP) is becoming more important. However, many patients die in hospital regardless of their desire to die at home. The purpose of this study was to clarify the difficulties in implementing ACP and the factors that inhibit respecting the wishes of the patient, based on the practical experience of visiting nurses who provide home care support.

Design: A qualitative descriptive study

Methods: The participants were 12 visiting nurses who met the inclusion criteria: having at least 3 years of home care nursing experience, experience practicing ACP, nursing for end-of-life care at home, and high interest in ACP. The survey was conducted in October 2022. Data were analyzed by qualitative inductive analysis. The ethics committee of the first author's institution approved the study.

Results: The participants had a mean of 11 years of visiting nursing experience (range, 3-20 years). Two were male and 10 were female. Five categories were generated as challenges faced by home visiting nursing users and their family, and included resistance of users and their family to discussing the end of life. Three categories were generated as challenges faced by visiting nurses themselves, and included difficulties in building a good relationship with patients. Challenges in regional cooperation consisted of five categories, including disagreement in perceptions among stakeholders and difficulties in cooperation among multiple disciplines including hospital doctors. One of the five factors that prevented the realization of wishes for end-of-life care at home was inappropriate care by family members.

Conclusion: Community-wide efforts are needed to implement ACP, because challenging issues were related to users/family, nurses, and regional collaboration. If patients wish to remain at home until the end of their lives, it is important to provide the appropriate support to family caregivers.

There are no conflicts of interest to declare.

ID: 245

Abstract Type: Oral presentation

Topics: Research methods, Artistic and creative approaches

Keywords: creative and relational resources, music therapy, selfhood, existential health

Caring for music – an international ethnography of dying people's creative and relational resources in palliative music therapy

Wolfgang Schmid

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Background: While there is a growing and compelling body of research on music, health and wellbeing, we still know very little about *how* and *why* people actually engage with artistic and creative media like music at the end of their life.

Objectives: The international ethnography *C4M - Care for Music* addresses these questions by intentionally upending the standard perspective of researching *what music does for/to dying people*, and rather asks *how, why and with what consequences people care for music at the end of their life.* Hereby palliative music therapy is conceptualized as cultural practice adapted to specialist settings and the needs of the people therein. Rather than as clinical intervention, music is understood as a complex aesthetic and social phenomena that can only be fully grasped *in-situ* and *in-action.*

Design and methods: From 2019-2023 we conducted an ethnography of people's actual engagement with music at the end of their life. Overall, we used *gentle methods*, including the collection of field and observational notes, video- and audio-recordings of music therapy sessions, and reflexive interviews with participants across two hospices. In a participatory micro-analysis of the wide-ranging data material, researchers and participants engaged in a circular co-analysis, refining and defining findings collaboratively.

Results: We collected and analyzed over 1000 hours of field observations, video- and audio-recordings of music therapy sessions. Through the participatory analysis, we found that dying people actively and resourcefully engage with and through preferred, biographically important music to care for themselves and for others, namely for their families. We will illustrate these findings with two case studies from the project including audio and visual material and discuss them with reference to the theoretical concepts of *selfhood* and *existential health*.

Conclusions: Finally, referring to the title of the conference, we address the questions of what we can learn from dying people's care for music, and how their capacity for engagement and agency in music therapy can invigorate broader societal discourse and awareness for the value of death and the recognition of dying people's creative and relational resources in end-of-life care.

ID: 246

Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, Policy and advocacy

Keywords: end-of-life-doula, collaboration, community, holistic, compassionate communities

Reimagining death care for our ageing population

Rebecca Jane Lyons

Solace End of Life Services, Australia

Background: What are the policy considerations for integrating medical and social care to transform the way we care for older Australians at the end of life? The Churchill Trust provided fellows an opportunity to present new policy ideas to the Australian parliament. My 2022 policy paper was launched at Parliament House and it identified that there was no public policy in Australia that integrated medical and non-medical services at end of life.

Objectives: This presentation explores the development of a policy framework to support the integration of medical and non-medical services and supports at end of life, taking a holistic and community-based approach to supporting people at the end of their lives.

Design: There are several ways in which formal and informal services can be integrated to the benefit of the community. This can include the engagement with compassionate communities, mobilising volunteer and wider community networks, collaboration with other charities and organisations – often it is about listening and then taking steps to rewrite policy, reconsider direction and rethink service provision.

Methods: My paper proposes bringing together both medical and non-medical stakeholders to co-design a holistic client-centred policy approach which includes:

- investigating the infrastructure needs to adequately support people to die at home;
- developing the resources/education required to support families and communities who choose community and family led home funeral and after death care;
- formulating strategies to promote the inclusion of end of life doula services as part of aged care and Care packages; and
- expanding the scope of existing death literacy and advance care planning programs and services to include the non-medical supports for end of life care.

Results: This project has received bipartisan support from politicians on both sides of politics in State Government within Australia; discussions are now being had as to how this can be trialled. Additionally, there is an aged care provider considering the re-write of their policies to include an integrated, holistic approach to living and dying in aged care.

Conclusion: This policy initiative of integrated end of life care is an Australian first. Already, governments and industry have acknowledged the need to include both medical and non-medical approaches in order to provide the best care possible to clients. It is now time to consider how exactly, we do this.

ID: 247
Abstract Type: Poster

Topics: Policy and advocacy, Care in humanitarian contexts

Keywords: cancer screening, integrated, SRH, earthquake

An integrated approach in Nepal earthquake response: Ensuring cervical cancer screening within the comprehensive sexual and reproductive health services package at Jajarkot and Rukum West districts of Nepal

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Background: The Family Planning Association of Nepal (FPAN), member association of International Planned Parenthood Federation, is a lead sexual reproductive health (SRH) service provider in Nepal. The maternal and neonatal health is integral part of the core programs and Minimum Initial Service Package (MISP) during humanitarian setting. FPAN ensures comprehensive SRH services through client-centered approach and well-trained service providers.

Objective: Ensure cancer screening integrated within the SRH service package for the earthquake affected indigenous tribal population of Jajarkot and Rukum West districts of Nepal.

Design: FPAN implemented three-month emergency response in two districts with the support from the SPRINT Project, providing promotive, preventive, curative and rehabilitative services including diagnostics on a range of essential SRH components.

Method: Coordination with the local government-rural municipal corporations, councils and partners for scheduling medical camps in hilly terrain and leveraging the community healthcare workers for generating awareness and mobilized communities for seeking SRH services were instrumental in increasing the reach during earthquake response. Considering this as an entry point and reaching the masses, FPAN service providers screened eligible women for cervical cancer using visual inspection with acetic acid (VIA) technique to identify high-risk positive cases, which are referred to higher centers for further management.

Results: Over 2,300 (male-356, female-1,944) clients benefitted with 18,802 SRH services, including gynecological-7,299, HIV-904, STI-6,683, pediatric-453, fertility-81, antenatal and postnatal care. Over 7,299 cancer screening services were provided including 1,310 cervical cancer using VIA, 463 breast cancer counselling, and 66 manual breast examination.

Conclusion

- Provision of integrated and client-centered approach for lifesaving SRH services to the crisis affected population.
- Awareness raising of the communities, especially vulnerable and marginalized groups on SRH.

- Strengthen the local institutional capacities and preparedness implemented in close coordination with the stakeholders for provision of comprehensive SRH services including cervical cancer screening.

ID: 248

Abstract Type: Oral presentation

Topics: Research methods, Networks and compassionate communities

Keywords: death literacy, compassionate communities, action research, co-researchers

Enhancing end-of-life care through community engagement and research – a study protocol

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Background: Efforts in our region strive to fill gaps in end-of-life care competencies in the population, aiming to establish a compassionate community. This initiative, driven by citizens, regional hospice, palliative care networks, and academic partners, involves publicizing end-of-life care concepts in political arenas and public talks.

Objectives: The project's goal is to empower individuals and communities in end-of-life care, enhancing their ability to support and shape experiences around dying, death, and bereavement. It also seeks to evaluate the effectiveness of a co-creative research approach, addressing challenges in merging academic and community objectives.

Design: Adopting a participatory approach aligned with Action Research, the project will reflect the needs of the regional population and service providers. The research team includes academic investigators and patients, caregivers, and local service providers - who do not possess specialist research training - acting as co-researchers.

Methods: Key methods include validating the German Death Literacy Index, assessing community readiness to address end-of-life issues, and evaluating the effectiveness of participatory research. The co-research team will define problems, identify strategies, and implement and evaluate educational, informational, and peer-support measures, guided by an external expert in participatory process management.

Results: The project will provide insights into community end-of-life competence and readiness and will validate a tool for assessing death literacy. It will establish a compassionate community model, facilitating access to end-of-life training and information and attracting attention for end-of-life themes, and developing new empowerment initiatives.

Conclusion: There may be challenges in collaborating on activities with varying academic and community goals and target groups, including the public, diverse patient groups, service providers, and policymakers. We will recognise them in aligning academic and community goals and will address them through team education, open dialogue on potential conflicts, collaborative goal-setting, and expert advisory support.

Funding: The project has been proposed for funding and is currently unfunded. No conflicts of interest are declared.

ID: 249

Abstract Type: Oral presentation

Topics: Death and grief literacy

Keywords: Death literacy, translation, validation, end-of-life care

Translating and adapting the Death Literacy Index in Belgium, the Netherlands and Sweden: characteristics and challenges

Therese Johansson[1,2], Steven Vanderstichelen[3,4], Carol Tishelman[3,5], Åsa Olsson[1], Corine A. Nierop-van Baalen[6], Marieke Groot[6], Lars E. Eriksson[1,7], Ida Goliath[1,8], Joachim Cohen[3]

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Background: Death literacy is a multidimensional construct conceptualizing broad non-professional competence and preparedness for engaging in end-of-life care and support. It is operationalized in the Australian self-report instrument Death Literacy Index (DLI), which has gained international interest as a potential outcome measure for end-of-life competence-building interventions but has hitherto not been adapted for mainland European contexts.

Objectives: The aim of this study was to translate, adapt, and establish the content and cognitive validity for the DLI in Flemish Belgium (FL), the Netherlands (NL), and Sweden (SE), and to examine the impact of health system characteristics on the DLI and challenges in adapting it to national contexts.

Design: International multi-step validation study.

Methods: Content validity was determined using a digital survey questionnaire among palliative care experts and by calculating the Content Validity Index for the whole instrument (S-CVI). Cognitive validity was determined using qualitative stakeholder interviews. Differences and challenges in adapting the DLI to each country were compared and discussed during international team workshops.

Results: In total, 33 experts (FL: N=15; NL: N=8; SE: N=10) participated in the content validation survey, and cognitive validity interviews were held with 31 stakeholders (FL: N=12; NL: N=9; SE: N=10). Translated items were considered relevant, clear, linguistically and culturally equivalent by experts, resulting in high S-CVI scores (FL=0.938; NL=0.864; SE=0.926). Challenges identified in the surveys and cognitive interviews centred around semantics (e.g., ‘community’, ‘the law’), the variation in legal and regulatory systems and the different services involved in death care in the different death systems, and differences in perceptions of who is responsible for care provision.

Conclusion: Comparing findings between the three countries emphasised how the nation-specific DLI’s are rooted in their death systems and problematised tacit knowledges embedded in the instruments. DLI adaptation remains a balancing act between instrument specificity and flexibility to allow comparison and maintain validity over time.

ID: 250
Abstract Type: Poster

Topics: Death and grief literacy

Keywords: Psychometrics, Cross-cultural equivalence, Death literacy, End-of-life care, Death education

Equivalence of construct validity of the Death Literacy Index in Belgium, the Netherlands, and Sweden

Therese Johansson[1,2], Steven Vanderstichelen[3,4], Aleksandra Bujazc[5], Leo Kowalski[5], Carol Tishelman[3,5], Corine A. Nierop-van Baalen[6], Marieke Groot[6], Åsa Olsson[1], Lars E. Eriksson[1,7], Ida Goliath[1,8], Joachim Cohen[3]

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Background: Death literacy is a multidimensional construct conceptualizing broad non-professional competence and preparedness for engaging in end-of-life care and support in civil society. It is operationalized as a six-factor model in the Australian 29-item Death Literacy Index (DLI). The DLI has gained international interest as a potential outcome measure for competence-building interventions related to the end of life, but it is not yet known whether death literacy is understood and measured in a comparable manner across countries.

Objectives: The aim of this study was to translate and adapt the DLI in Flemish Belgium (FL), the Netherlands (NL), and Sweden (SE) and to examine cross-national equivalence (also called measurement invariance) of the theorized six-factor model across national samples.

Design: International cross-sectional survey with nation-based quota samples of adults recruited from a European online panel agency.

Methods: Survey responses were analysed using multigroup confirmatory factor analysis.

Results: Country-specific DLI versions were developed through an iterative multi-step translation and adaptation process. The nation-specific DLIs were completed by 1516 participants (FL=502; NL=511; SE=503). The six DLI subscales showed satisfactory reliability and the six-factor model had good fit in each sampled country. The DLI met conditions for configural invariance (comparative fit index (CFI)=0.968, root mean square error of approximation (RMSEA)=0.067), scalar invariance (ΔCFI=-0.001, ΔRMSEA=-0.003), and metric invariance (ΔCFI=0.001, ΔRMSEA=-0.002). All but one item had strong (>0.60) factor loadings to their hypothesised scale; for six items factor loadings differed by ⩾0.1 between countries.

Conclusion: We found the DLI's measurement of death literacy was equivalent without systematic bias across the three national samples. This finding suggests that death literacy can be a relevant and comparable cross-cultural construct for community preparedness and self-efficacy for engaging with end-of-life care. Our study provides initial support for using the DLI to make cross-national comparisons of death literacy and its potential as an appropriate instrument for evaluating impact of competence-building interventions internationally.

ID: 251
Abstract Type: Workshop

Topics: Networks and compassionate communities

Keywords: compassionate communities; death; public health; culture; community; palliative care

Building a compassionate Community: where do I start?

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Target audience

1. Participants wishing to start compassionate communities in their set up
2. Participants who already have compassionate communities in their set up
3. Participants who run compassion programs in their set up

Learning objectives

1. Expand knowledge on compassionate communities
2. Sharing experiences on compassionate community programs
3. Develop a check list for starting a compassionate community

Structure of the workshop

1. Introduction – 15 minutes

The facilitators will introduce the participants to each other then the concept of compassionate communities. Compassionate communities are rooted in a health promotion approach to palliative care and encouraging end of life care within communities. In many cultures, taking care of the sick and dying was done within communities and in the past cultures had ways of supporting such individuals and families. The culture evolved due to colonization, modernization, education and uptake of religion. Many individuals now live and work in urban centers. Research shows that many patients still prefer to die at home but this is often not possible due to perceptions within communities. It is perceived as neglect when a patient dies at home and other challenges such as lack of caregivers or living in rental houses also makes it difficult to honour wishes of the dying. Many individuals end up dying in hospitals surrounded by healthcare providers and medical machines.

Compassionate communities is therefore a public health approach to provision of palliative care by creating interactions between palliative care providers, local or government administration and communities.

2. Sharing experiences – 15 minutes

The facilitators will ask participants to give their experiences on starting or running compassionate communities. The focus will be on how they started, what has worked for them and what lessons they have learned. These can be shared by upto 5 participant.

3. Developing a check list – 30 minutes

The participants will be split into smaller groups of about 7 – 10 participants and asked to discuss for 10 minutes and create a check list of items, resources, personnel that are crucial before starting a compassionate community. The session will be wrapped up by presentations from the group and creating one checklist.

ID: 252
Abstract Type: Poster

Topics: Death and grief literacy, Educational approaches

Keywords: End-of-life health literacy, knowledge, advance care planning

How can I choose? Personal end-of-life health literacy; a key factor for advance care planning

Clément Meier[1,2], *Sarah Vilpert*[1], *Maud Wieczorek*[1], *Carmen Borrat-Besson*[2], *Ralf J. Jox*[3], *Jürgen Maurer*[1]

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of Humanities in Medicine, Lausanne University Hospital and University of Lausanne

Introduction: Population aging, technological advancements, and an increasing emphasis on patient empowerment imply that individuals are increasingly confronted with intricate end-of-life decisions. Personal end-of-life health literacy skills may help empower individuals to participate more actively in their own end-of-life decisions, including engagement in advance care planning (ACP). This study thus investigates the associations between individuals' end-of-life health literacy and their knowledge and behaviors toward ACP among a population-based sample of adults aged 58+ in Switzerland.

Method: We used data from 1,319 respondents from Wave 8 (2019/2020) of the Survey on Health, Ageing, and Retirement in Europe. Subjective end-of-life health literacy was measured using the S-EOL-HLS scale. Respondents' end-of-life knowledge was assessed using test-based questions about 11 end-of-life medical situations. Behaviors toward ACP were measured by whether respondents have discussed their end-of-life wishes, completed advance directives (AD), and appointed a potential surrogate for medical decisions in case of incapacity. Associations were estimated using separate ordinary least square and probit regressions, controlling for social, health, and regional characteristics.

Results: Respondents with higher end-of-life health literacy tended to have better end-of-life knowledge and were more likely to have discussed their end-of-life wishes, to have completed AD, and to have appointed a surrogate for medical decisions in case of incapacity. Upon regressing the outcomes on the three end-of-life health literacy dimensions, interactive health literacy positively correlated with end-of-life knowledge and the three behaviors toward ACP, while critical health literacy was only associated with having an AD and appointing a surrogate for medical decisions.

Conclusions: Our findings suggest that end-of-life health literacy may play a significant role in individuals' level of end-of-life knowledge and their behavior toward ACP. Thus, developing public health policies aimed at strengthening their end-of-life health literacy skills may increase individuals' engagement in the ACP process and make ACP more effective.

ID: 253

Abstract Type: Oral presentation

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: End of life, health literacy, caregivers, experiences, family care

Learning by Experience: Does caregiving for loved ones boost personal end-of-life health literacy?

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Background: Despite the critical role of health literacy in utilizing palliative care, engaging in advance care planning, completing advance directives, limited research exists on the determinants of end-of-life health literacy.

Aim: This study investigates the association between individuals' experiences with end-of-life care support to loved ones and end-of-life health literacy among a population-based sample of adults aged 58 and older.

Design: Observational study.

Setting/Participants: We used data from 1,548 respondents to Wave 8 (2019/2020) of the Survey on Health, Ageing, and Retirement in Europe in Switzerland. The respondents' ability to understand medical jargon, find information, communicate, and make decisions about end-of-life care options was measured with the Subjective End-of-Life Health Literacy Scale. Experiences with end-of-life care support include having made medical decisions as a healthcare proxy, accompanied, or cared for a loved one at the end of life. Associations were estimated using ordinary least squares regressions, controlling for socio-demographic, health, and regional characteristics.

Results: Respondents who experienced being a healthcare proxy ($p<0.001$), who accompanied ($p<0.001$), or who cared for a dying relative or close friend ($p<0.001$) tended to have higher levels of end-of-life health literacy. These results remained significant when the three variables were simultaneously included in the multivariable model ($p<0.001$, $p<0.001$ and $p<0.05$).

Conclusions: Our findings suggest that providing end-of-life support to loved ones is associated with higher end-of-life health literacy. Thus, as caregivers gain experience caring for others, targeted interventions could leverage their skills and encourage them to think of engaging in end-of-life planning for themselves.

ID: 255
Abstract Type: Oral presentation

Topics: Educational approaches

Keywords: MOOCs, massive open online courses, online learning, palliative care education

Harnessing the potential of Massive Open Online Courses (MOOC) for global palliative care education - a scoping review

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Background: Massive Open Online Courses, or 'MOOCs', have gained growing popularity over the last ten years. Capable of an almost universal reach and freely accessible across the world, MOOCs have a huge potential to promote public awareness and engagement in palliative care and facilitate continuing professional development among health professionals. The aim of this scoping review is to identify MOOCs focused on improving knowledge of palliative care, and associated published literature, to further understand the potential of MOOCs in palliative care education.

Methodology: A scoping review approach. Two review questions were identified; firstly, what are the characteristics of MOOCs focused on palliative care, and what literature is available on the development, delivery, and utility of such MOOCs. Eight online databases were searched to identify peer reviewed literature on the topic, which were analysed using narrative synthesis.

Results: Fifteen MOOCs were identified online, of which four were referred to in the twelve peer reviewed papers identified in this review. Seven papers focused on research embedded within the MOOC, two papers focused on MOOC development, two on motivation for participation and knowledge development, and one on using MOOCs for research dissemination and the development of recommendations for practice in palliative care.

Conclusion: MOOCs have immense value to palliative care education in terms of accessibility, flexibility, and cost, with a clear potential to reach a global audience of both the public and health care professionals. Further empirical research is needed to explore embedding research into MOOCs, developing content specific to the needs of health professionals and how to further utilize the opportunities for palliative care education that MOOCs present.

ID: 256
Abstract Type: Poster

Topics: Policy and advocacy, Care in humanitarian contexts

Keywords: Indigenous People, Access to sexual and reproductive health services, Earthquake affected area, Jajarkot and West Rukum District, Nepal

Enhancing access to sexual and reproductive health services among indigenous people in earthquake-affected area of Jajarkot and West Rukum district, Nepal

Chet Raj Joshi
Family Planning Association of Nepal, Nepal

Background: The Family Planning Association of Nepal (FPAN), member association of International Planned Parenthood Federation, is a national non-governmental organization specializing in provision of sexual reproductive health and rights (SRHR). FPAN responded to the 3rd Nov. 2023 earthquake in Jajarkot and West Rukum districts of Nepal with SPRINT project support through provision of essential lifesaving SRH services, especially for the vulnerable and marginalized population residing in remote and hillside earthquake-affected areas. Limited access to family planning, safe-abortion, HIV/ STI, GBV and obstetric care can lead to increase in preventable morbidities and mortalities.

Objective: To assess the effectiveness of the comprehensive SRH services provided to the vulnerable groups, especially indigenous tribal population in the earthquake-affected areas of Jajarkot and West Rukum districts in Nepal.

Design: With the support from the SPRINT project, FPAN implemented the minimum initial service package (MISP) and organized 15 SRH mobile camps in coordination with the local government and stakeholders for a unified response.

Method: Using FPAN DHIS2 for collecting disaggregated service statistics the data was analyzed to identify proportion, trends, and pattern in SRH service utilization.

Results: Till December 2023, FPAN reached 2,300 individuals (1,944 females, 356 males) with a total of 18,820 SRH services. These include 25 persons with disabilities, 1,098 indigenous persons and 77 pregnant and lactating mothers. Major services include, gynecology-7,299 (39%), STI-6,683 (36%), family planning-1,409 (7%), HIV-904 (5%), and obstetrics-285 (2%) services. 10 to 19 years clients constituted 3%, while 20 to 24 years were 9% and above 25 years were 47%. Affected population were mobilized through the community healthcare workers.

Conclusion:

- Mobile camps were designed to prevent and address essential SRH needs including gender-based violence, which are exacerbated during disasters.
- Integrated psychosocial support within the comprehensive SRH services can have profound effects on the affected population.
- Reviewing the programmatic data helps in identifying the unmet needs and re-strategizing the response intervention and advocacy, contributing to improving the overall health outcomes.

ID: 257
Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: community engagement, comparative ethnography, compassionate communities, implementation, public health palliative care

Community engagement in public health palliative care: Results from a comparative ethnographic study of two Compassionate Communities in Canada

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Background: Compassionate Communities are practical examples of public health palliative care that aim to bridge the gaps in access, quality, and continuity of care in the context of serious illness, end-of-life, loss, and grief. There has been research on Compassionate Communities for over 20 years, but community engagement, as a core principle of public health palliative care, has received little attention in empirical studies.

Objectives: The objectives of the presentation are to describe the evolution of community engagement processes in different contexts, its influence on the implementation trajectories, and the outcomes of two distinct Compassionate Communities in Canada.

Design & Methods: Anchored in a community-based participatory research approach, we developed a longitudinal comparative design using ethnographic methods to study how community engagement evolves in different Compassionate Community contexts. The multi-site ethnographic data set covers 337 hours of fieldwork, including participant observation (236 hours); interviews with key informants (n=26); and project logbooks (over 1500 detailed entries).

Results: Findings show that professionally-led initiatives focused on the implementation of existing programs “in” the community tended to create less community engagement and buy-in. Conversely, community facilitation focused on relationship-building among actors and strength-based asset development yielded intersectoral collaboration that fostered a stronger sense of community engagement and ownership. These trajectories, with their strengths and weaknesses, also appear to influence short-term outcomes and project sustainability in different ways. Results and outcomes from both implementation trajectories will be presented in relation to community engagement processes and initiatives’ sustainability.

Conclusion: These results highlight that the attitudes and behaviors adopted by compassionate community developers can promote or hinder community engagement. As such, these findings can be leveraged to engage communities in more meaningful ways. Thus, ensuring greater success, stronger impacts, and fostering more sustainable Compassionate Communities.

ID: 258

Abstract Type: Oral presentation

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: Death, Literacy, city, compassionate

Understanding death literacy in Birmingham city

Emma Hodges

Compassionate Communities UK, United Kingdom

Background: Birmingham has been a Compassionate City for two years. A group of people from over 15 organisations form the committee for Compassionate Birmingham Network (CBN). A key focus for 2023, was the use of the Death Literacy Index (DLI).

Objectives: to contribute to evaluating outcomes of CBN Activities, to inform discussions around community capacity building and to support improvements at system level. The target number for statistical significance was 386.

Design: The validated DLI tool was used. Two extra sets of questions were added: I) demographics including level of experience. II) their top three priorities in situations regarding serious illness and bereavement.

Methods: The link to the survey was sent to the CBN and distributed to citizens and organisations. The survey was also sent out on social media. The survey results were analysed in a variety of ways; i) reporting on individual question results, ii) using the standard evaluation tool designed as part of the DLI. iii) Analysis of the demographic and experience questions. iv) Analysis from the priority questions

Results: 391 people completed the survey. It was accepted that in this phase diversity of participants would be limited. One of the concerns about the method of data collection was that a high number of participants would be health and care professionals. This wasn't the case and the number of people who had significant or limited personal experience was evenly distributed.

Based on the participants, the questions related to 'talking confidence' and 'practical hands on support' scored well. However, when the questions started to ask about factual knowledge and access the results were reversed. This demonstrated that how information has been shared has not been effective. On the questions related to priorities, the data demonstrated the importance of emotional support, social connectedness and time with friends and family being of greater importance than other elements such as physical care or pain relief.

Conclusion: The results are feeding into strategic developments around how information is shared with citizens in a meaningful way. Whilst a significant number of people completed the survey, the data is not representative of the diversity of the City. The aim of phase one, was to gain broad understanding. The CBN is now focusing on smaller localities and marginalised communities. The next phase will include a specific neighbourhood and people identifying as LGBTQIA+.

ID: 259

Abstract Type: Oral presentation

Topics: Artistic and creative approaches, Care in humanitarian contexts

Keywords: drawings, Covid-19, phenomenography, children and adolescents, end-of-life

Drawings about end-of-life issues: Analysis of pictures by children in Sweden during the 1st Covid-19 wave

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Background/Objectives: The Covid-19 pandemic and its containment measures significantly affected children. However, few studies gather data directly from children, instead relying on proxy reports from adults. Prior research noted children tended to be shielded from end of life (EoL)-related issues during the pandemic; however, death-related imagery was a notable part of children's drawings from that time. We therefore explore the variation in depictions of EoL issues in drawings by children in Sweden during the 1st pandemic wave.

Design/Methods: In March 2020, the Swedish Archive of Children's Art called upon children to submit artwork about their perceptions, feelings, and experiences during the Covid-19 pandemic. After examining all 1154 submissions, a transdisciplinary research team inductively conducted a serial analysis of all drawings with recognizable portrayals of EoL issues, i.e. sickness, care, dying, and death (n=172). The analysis was inspired by a phenomenographic approach, aiming to explore qualitatively different ways people conceptualize, experience, and understand various aspects of phenomena around them.

Results: We found 2 qualitatively different types of portrayals. The 1st type focuses on (re)actors in the pandemic, depicting the virus as an, often aggressive, active agent, while humans, including health professionals, are reactive, appearing passive and at a loss. Notably few drawings show nonprofessionals as active or as carers. The 2nd type of portrayal focuses on pandemic victims. The largest group by far depicts victims as unknown, e.g. as statistics or by unidentified graves. To a lesser degree, victims were depicted as known to the children, and a few children depicted themselves as victims, e.g. drawing their own gravestone.

Conclusions: Drawing supports a process of reflection, even about EoL-related issues. A subset of children appear aware of EoL issues, depicting questions, concerns, and fears, although those close to them seem not (yet) directly affected by Covid-19. Children appear to react to the powerlessness of adults, including professionals, which reflects the situation and discourse at the time. Instead of assuming children's lack of awareness of EoL issues, it seems more constructive to address such issues in a child-centered manner and equip adults with necessary tools for communication.

ID: 260

Abstract Type: Oral presentation

Topics: Educational approaches

Keywords: education, palliative care, action learning, end-of-life care

Patient-Centred Hospitals: an innovative training programme for integrating comprehensive and palliative care in healthcare facilities ((QELCA©) Programme)

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Background: In Argentina, only one in ten people needing palliative care (PC) receive it. The (QELCA©) Programme (Quality End of Life Care for All) was designed to support the development of skills and confidence in those unfamiliar with PC, aiming to overcome institutional, care, and cultural barriers.

Objectives: In two public hospitals in Buenos Aires, Argentina, the (QELCA©) programme aimed to promote attitudes and competencies towards holistic care, recognising the suffering linked to health and illness. It focused on establishing a comprehensive approach, defining key aspects, and planning action plans to improve care quality.

Design: An Argentinian NGO, a leader in PC education in the region, in alliance with a British Hospice, implemented the (QELCA©) to increase the number of institutions that can successfully implement a culture of comprehensive and active quality care, according to the international standards defined by the WHO.

Methods: A team of PC experts implemented a coaching process to rethink the reality of each participant and identify what competencies they need to develop. The Muñiz Hospital of Infectious Diseases (2020) and the San Fernando General Hospital (2022) participated in 5 face-to-face days of 4 hours/day, using the Action Learning Sessions; 12 months of subsequent virtual monitoring by the experts and 12 meetings via Zoom. It combined highly interactive, classroom-facilitated learning and practical observation.

Results: Two hospital-specific PC multidisciplinary teams emerged from the intervention focused on communication, a comprehensive approach to patient families, understanding the unit of care as a patient family, interdisciplinary work, and decision-making. The changes produced included creating a comprehensive and interdisciplinary care group with its own identity in both hospitals, improved communication within the team and with the patient-family, a comprehensive approach to patients, and improved decision-making processes related to end-of-life situations.

Conclusion: The recent experience of implementing the (QELCA©) in two Argentinian public hospitals is a convincing demonstration of the programme's benefit to our environment. Key factors for the success of the implementation included identifying people who commit to carrying out an institutional project, the continuity of meetings, and the importance of monitoring at a personal level and not only in the group (action plan) in this context.

ID: 262

Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, Policy and advocacy

Keywords: Acute hospital care, discharge, collaboration, palliative care

Palliative care in the acute admission setting

Rebecca Newell[1,2], *Paul Pascal Jones*[1,2], *Ellie Evans*[2], *Molly Stewart*[1,2], *Nicola Henawi*[2], *Rachel Craig*[1,2], *Philip Lodge*[1,2]

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Background: Despite most people in the UK reporting a preferred place of care and death as home, in 2021 nearly three quarters of those who died spent some time in hospital during the last 6 months of life. In increasingly busy and stretched acute hospital services, it can be challenging to recognise, adequately support and discharge patients approaching the end of life.

Objectives: To trial the integration of palliative care into the acute medical setting. Our hypothesis was that proactive and early palliative care input could promote patient centered care, promote early discharge and advanced care planning (ACP) and improve complex symptom management.

Design: A pilot study was completed at a London hospital with members of the palliative care team (PCT) proactively seeing patients within the acute medical and emergency departments (ED). Inclusion criteria for review was deliberately broad, but included a prognosis of less than one year, symptom concerns or a request for ACP.

Methods: A scoping exercise was done through spending time with the acute medical and ED teams, attending handovers and discussions with key stake holders. We retrospectively audited patient admissions, who had subsequently died, and proactively audited the patients we saw for a quantitative comparator. We led peer-to-peer teaching with the acute medical and ED teams.

Results: The service prompted direct ED discharge of 3 patients, and a further two were referred to a hospice within one working day of admission. The length of stay was 11 days in the retrospective audit and 5 days for those seen by the service. ACP and community palliative care referrals additionally increased. This enabled patients to be in their preferred place of care. We promoted service integration between community, primary and secondary care services. We hypothesise our service would reduce admissions and bed day costs if upscaled.

Our ability to effect change was limited by internal and external factors including hospice waiting times, availability of community social care, and the uncertainty that acute medical illness poses. Our comparative data has self-selection bias as we proactively sought patients for palliative care input.

Conclusion: As acute medical services continue to face increasing pressures, palliative care in acute settings can help through supporting the recognition and management of patients approaching the end of life, encouraging proactive discharge decisions, early ACP and supporting staff.

ID: 263

Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, Death and grief literacy

Keywords: Care service use, family carers, experiences, bereavement

Experiences of care service use in the last three months of life: findings from a national post-bereavement survey in England and Wales

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Background: Post-bereavement surveys are a validated method for understanding care and support experienced by people approaching the end of life, especially if a nationally generalisable sampling frame is used.

Objectives: To describe the use, experiences, and outcomes of end-of-life care in the last three months of life among decedents in England and Wales.

Design: Cross-sectional post-bereavement survey (modified QUALY-Care) using a stratified nationally representative sample of decedents, excluding sudden deaths.

Methods: The survey was disseminated in 2023 by the Office for National Statistics to 3000 adults who had registered a family member's death 6–10 months prior. Data were analysed using descriptive statistics.

Results: 1179 responded (response rate 39.3%). 61.9% of those who died spent most of their last 3 months at home. 54.7% used an ambulance and 59.0% attended the emergency department once or more. 12.4% spent more than 30 days of their final 90 in hospital. 86.3% had contact with community-based primary care professionals: but 19.3% had no contact with a GP. Specialist palliative care was received by 45.1%, more often by those who died from cancer (83.6%) and less often by those aged 85 or over (38.2%). Only 42.5% had a care coordinator, and 37.6% struggled with accessing care. 17.9% of respondents had been unaware that their relative was dying. For 37.8% of those who died, and 29.6% of the respondents, health care professionals had not discussed death and dying. In the final 3 months of life, 74.7% received care from the respondent and 53.3% from additional family members/friends. Caring often had a financial impact: 48.8% of the respondents in paid employment took paid or unpaid leave or changed their work hours. Disturbed grief was indicated for 15.6% of respondents, more commonly among those with poor care experiences.

Conclusions: Overall, we found that many experience difficulties accessing the care and support needed at the end of life. We found issues with access to and coordination of care and support at the end of life. Lack of resources, compounded by inadequate communication and poor coordination, results in high levels of unmet needs among those at the end of life and distress and increased care burden among their carers. To improve services, health and social care professionals must have sufficient time, skills, and resources to provide end-of-life care, across settings.

ID: 264
Abstract Type: Oral presentation

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: grief literacy, equipping, 95%, community, national

Grief Kind-bringing grief literacy into people's living rooms and lives

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Sue Ryder, United Kingdom

Sue Ryder (SR), the UK's bereavement charity, started its Grief Kind campaign in 2021, after research found that people struggled to support other who had experienced a bereavement. Grief Kind aims to educate the nation to meet grief with warmth, rather than shying away from conversations. SR created a TV ad to ensure grief is something that is normalised and talked about in the UK households. This has been watched by millions of people across the UK and has increased traffic to the website and sign ups to our online bereavement services. In October 2021, we launched our Grief Kind podcast series. In each episode, a SR Ambassador was joined by a celebrity who reflected on their bereavement journey and talked about who helped them through grief. To date, we had over 100,000 downloads. In 2022, SR launched Grief Kind classes, 5 short video tutorials, in which our SR bereavement experts talk viewers through what grief is like and how you can support others who are grieving. Viewed over 37k times, they provide valuable support to organisations and individuals to be Grief Kind. In 2022, SR launched The Empty Chair campaign, an exhibit with a dining table surrounded by 13 empty chairs that encouraged the public to be Grief Kind and offer those who are grieving a chair at their dinner table. The powerful exhibit made a real impact with coverage reach totalling 9.5 million+. It was taken to parliament to engage with MPs to encourage them to sign up to be more Grief Kind. Other public engagement campaigns included installing a red London phone box on Brighton seafront to encourage people to be honest about their feelings of grief and an artistic campaign to show how the senses can impact people's grief when they least expect it.SR also places regular grief advice and thought leadership pieces in the media. A recent radio day reached over 9 million people. Grief Kind allows for lobbying work with the government, raising the profile of grief and what people need: bereavement leave, service pathways or grief on the school curriculum. Recently, SR has set up Grief Kind spaces across the UK, offering peer-to-peer support groups in cafes, hotels and local community centres. This public health campaign continues to grow and develop and has inspired services worldwide to use the materials and resources. It meets people where they are - shopping, walking by the sea, waiting for a bus, in their home or workplace and tackles issues important to raise and offering guidance.

ID: 265

Abstract Type: Oral presentation

Topics: Policy and advocacy, Research methods

Keywords: Health policy, Access, Palliative care, Health systems, Advocacy

Access to palliative care in India: a time to travel analysis of 526 non-governmental palliative care facilities in India

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Background: The burden of non-communicable diseases like cancer, diabetes, and hypertension is rising rapidly in India. Annually, 7.2 million Indians with end-stage disease need palliative care. Estimates suggest that less than 1% of these people receive palliative care in the country. Yet, research on access to palliative care services is missing.

Objective: To estimate the travel time to the nearest non-governmental palliative care center (PCC) - as a proxy of geographic access - across 36 Indian states and union territories (UTs).

Design: Geospatial modeling study.

Methods: Data on 526 non-governmental PCCs were collected and harmonized by Pallium India in November 2022. Geolocations were manually coded and validated. Our analytical pipeline combining multiple geodata resulted in two outcomes: a) median (interquartile range) travel time to the nearest PCC assuming motor vehicular transport and b) population % within 60 minutes of their nearest PCC using a motor vehicle. All findings were disaggregated by state and rural-urban residence.

Results: Nationally, the median (IQR) time to reach the nearest PCC was 118 (71-179) minutes. The median time to reach the nearest PCC was nearly double for rural (120 (72-180) minutes) as compared to urban areas (57 (16-108) minutes) and was the highest for the union territory of Ladakh (591 (412-881) minutes) and lowest for the union territory of Lakshwadeep (1 (1-2) minutes). The time to access in rural areas was worse compared to urban areas in all states. 39.9% of the Indian population had access to the nearest PCC within 60 minutes using a motorized vehicle. The urban population (68.3%) had better access than the rural population (29.3%). All Chandigarh and Delhi residents were within 60 minutes of their nearest PCC compared to 14.5% of Arunachal Pradesh residents. 22 states/union territories had less than 50% of the population within a 60-minute ride to the nearest PCC.

Conclusions: In this novel pan-India analysis, we found that PCC access varies widely across states and is poor for rural areas. The work has direct implications for targeted resource allocation and palliative care infrastructure development for equitable access. Future studies should assess access to specific palliative care services like access to pain relief medications in the country.

ID: 267

Abstract Type: Workshop

Topics: Research methods

Keywords: Causality, impact, evaluation, change, intervention

Unpacking causality and impact in public health palliative care initiatives: Exploring research approaches

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Target Audience: All interested in qualitative approaches to explore impact of public health palliative care initiatives, including junior and senior researchers, practitioners and community members. This workshop builds on the Part 1 workshop, Unpacking Causality and Impact, but can be attended independently.

Learning Objectives include gaining understanding of:

- applications for, limitations of, and challenges associated with studying causal relationships and sustainability in change processes using qualitative approaches
- characteristics of 3 qualitative methods for impact evaluation and when they are most suitably used.

Workshop Structure delves into 3, predominantly qualitative, approaches for empirically examining impact and causality as follows:

Presentation of methods in terms of their focus, opportunities, and challenges

- Most Significant Change analyzes narratives detailing transformations from an intervention, deriving, through consensus, one story that contains the most significant change. The Attentive Visitors workshop, in which 19 interviews were conducted with volunteers who participated in a training program in Flanders, provides an example. The process of deriving relevant stories from these interviews and working with stakeholder organizations to reach consensus about most significant change will be discussed.
- Contribution Analysis is aimed at inferring causality in complex programs. Using an iterative process, it enables researchers, practitioners, and policymakers to identify the contribution an intervention, and additional factors, has on a particular outcome. A theory of change is generated at the start of the evaluation and subsequently confirmed or revised during implementation. Examples of its application in the UK will be provided.
- Ripple Effects Mapping is designed to actively involve program stakeholders in describing and visually mapping their perceptions of the effects of a program. Two examples of REM will be provided, exploring: i) the ripple effects stemming from Compassionate University (Belgium) and ii) a modified use of REM to study the dissemination of the DöBra cards (Sweden)

Interactive group sessions

- Facilitated hands-on practical exercises will be held to further delve into each approach. Attendees will have the opportunity to participate in one approach session.

Closing

- Summary of main lessons learned, with sources for other resources.

*EPICEUR= End of Life and Public health Initiative for Collaborative European Research

ID: 270
Abstract Type: Poster

Topics: Relationships and connection

Keywords: Cancer, disclosing diagnosis, family member views

Views of the family members about letting the patient know the diagnosis – An experience in a tertiary cancer centre in North East India

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Dr Bhubaneswar Borooah Cancer Institute, India

Introduction: Family ties are very strong in India. Every member take part in decision making and their views are considered. All members of the family come to know about the diagnosis first except the patient and they decide whether they want to divulge the truth to the patient or not. In almost all cases, the family members do not let the patient know. According to medical ethics, patient has the right to know about his disease and the status and our study is to find out the views 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 family members 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. From the patients' perspectives

– most of them wanted to know the diagnosis (13 out of 19)(68.4%). But 9 out of 19 relatives (47.4%) did not want to let the patient know 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 loose 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 views 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.

Keywords: Cancer, disclosing diagnosis, family member views.

Conflict of Interest and Funding: None

ID: 271
Abstract Type: Workshop

Topics: Policy and advocacy, Networks and compassionate communities

Keywords: Palliative Care Development, Paedia_ tric Palliative Care, Empowerment, Africa

Africa in the spotlight: empowerment of people and communities

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[1]University of Navarra, Spain; [2]African Center for Research on End of Life Care

WORKSHOP

Target Audience: policymakers, stakeholders for LMICs, health professionals, volunteers, the general public, NGOs

Learning Objectives: WHO Conceptual framework on PC development, variety of empowerment of people and communities in the LMIC context, building-up strategies together in Africa.

Structure of the Workshop: After the introduction of the workshop's objectives and participants (moderator Dr Vilma Tripodoro, Argentina/Spain), we will start with three short presentations, 10 minutes each, related to different aspects of empowerment of people and the community dimension.

The new dimension of WHO conceptual framework on PC development: Empower People and Communities and its outlook in Africa. (Dr. Fernanda Bastos, Brazil)

Empower Paediatric PC Communities in Africa: how does it differ from adult communities? (Dr. Julia Downing, Uganda - to be confirmed)

Palliative care empowerment in Africa: the last 20 years experience. (Dr. Christian Ntizimira, Rwanda).

Breakouts into small working groups discussing strategies for mapping local and/or regional organizations, building regional hubs and creating possible action plans to maintain a living collaborative network between all different stakeholders in the PC context. This 10-minute task will be followed by 5 minutes of SWGs exposition of their outcomes. The moderator will highlight the endpoints and close the session.

Reasoning: In 2021, WHO launched a new conceptual framework for PC development. This compounds six core dimensions of fundamental and equal importance. One novelty in this conceptual framework is the inclusion of 2 new dimensions: Research and EMPOWER PEOPLE AND COMMUNITIES. Giving voice to patients, families and communities helps health services, policies and research be more responsive and effective to population needs. This conceptual framework involves macro indicators to be assessed by stakeholders. It highlighted the existence of groups dedicated to promoting the rights of patients in need of PC, their caregivers, and disease survivors, in addition to the existence of national policy or guidelines addressing ACP of medical decisions for the use of life-sustaining treatment or EoL care. A constructive discussion from theoretical grounds with life-experienced participants should be fundamental for strengthening PC in the global healthy community.

ID: 272
Abstract Type: Oral presentation

Topics: Care in humanitarian contexts

Keywords: Beistand, Pflege für obdachlose Menschen

The “Leo project”- outreach care and support for homeless people in the Innsbruck area

Elisabeth Draxl
Tiroler Hospizgemeinschaft, Austria

Idea: Even, or especially, people on the margins of society suffer usually when they have multiple or severe illness at an early stage. Sometimes they are not insured and access to care services is difficult. They need low- threshold and flexible support, so that they too can benefit from hospice culture and palliative care. And often experience loving care and support for the first time in their final years.

Implementation: The “Leo project” (named after a person suffering from cancer, who was initially cared of the “Verein für Obdachlose”, then at hospice Tirol), was founded in 2022. The “Tiroler Hospizgemeinschaft”, association established the patronage. The basic principle is outreach care and support in the places where these people live and visit.

However, the “Tiroler Hospizgemeinschaft” facilities (day hospice, “Mobiles Palliativteam”, outpatient clinic,ward) are also available to sick people within a short distance if required. Early palliative care, a multidimensional approach, as well as trust and continuity of care are sought and made possible.

This is guaranteed by the cooperation with the association fort he homeless.

Medical care for the uninsured, basic medical care service provided by the Red Cross and Caritas.

Targeted social counseling is offered by the “Verein für Obdachlose”. Stays at the Hospice House are covered by “Tiroler Hospizgemeinschaft”.

The project is currently being implemented in the Innsbruck area. The specific support measures include accompaniment to doctors and hospitals. Possibly the return to he regular systems, “translation” of medical diagnoses and recommendations, organization of medication and aids. Care- especially wound care, acute interventions, sometimes just being there and listening. The project ist currently being financed by donations until 2026.

Conclusions/lessons learned: Many breaches of trust- it takes time to approach and build a relationship.

The topic of bringing people into the center of society.
Educational work – sensitizing society and the health system.
It needs housing for sick and uninsured people.
Involvement of those affected.
Development and training for volunteers.
Interdisciplinary approach.
Collaboration with all homeless and homeless assistance facilities.
Possibly scientific support
Compassion and solidarity.

ID: 273
Abstract Type: Poster

Topics: Death and grief literacy, Artistic and creative approaches

Keywords: co-design, bereavement, curation, art therapy, ethics

Material legacies: collecting, co-designing, curating and continuing bonds

Stacey Pitsillides
Northumbria University, United Kingdom

Material Legacies is a five-year collaboration with The Hospice of St Francis, UK that uses practice research methods to co-create a collection of experiential artifacts, four documentation films, a series of specialist talks and two public exhibitions with three bereaved makers. This research creates novel practices that redefine the role of artistic collaborations with the bereaved, creating alternative spaces for a person’s physical and digital legacy.

The research aims: 1. to explore how collections of things (objects and data) can be used as material to embody the relationship between the living and the dead 2. to use co-design, situated design and exhibition design to flatten hierarchies and provide a framework for studio making within these sensitive contexts 3. to reflect on the context between palliative care, art therapy and design in relation to the bereaved and their archives.

Material Legacies locates its approach to bereavement within continuing bonds theory, where the bereaved may explore a continued relationship with the dead (Walter, 1996). The narrative turn within hospice care (Gunaratnam and Oliviere, 2009) has potential to readdress the balance between “psycho-dynamic and artistic methods” (p.2), explored materially in art therapy literature (Mahony, 2001; Moon, 2010; Moon, 2016). Within this research a narrative approach is used to create conceptual prompts within the process of making – layering stories within the material as artifacts form and through the addition of sound and projection mapping. Documentation films [https://vimeo.com/222669034] also reflect on the nature of the collaborations and its role in the ethical narration of the research.

Using co-design acknowledges that the bereaved have a distinct and nuanced knowledge of their relationship to the loss (Sanders & Stappers, 2008) and tackles traditional hierarchies around client-based therapy. By reflecting on a sustained two-year co-design process with the bereaved, this research advocates that in sensitive contexts collaborators must have agency at all stages of the design process, otherwise as solutions or products begin to form they impose design decisions on the community rather than activate collaborations with them (Bowen et al, 2013). This paper explores the diverse formats needed to develop ethical design practices that incorporate digital and public engagement through transparency, personal choice and collaboration.

ID: 274

Abstract Type: Oral presentation

Topics: Research methods, Networks and compassionate communities

Keywords: Belgium, Canada, community engagement, compassionate communities, cross-cultural comparison

Cross-cultural perspectives on Belgian and Canadian compassionate communities: comparing results from two cousins initiatives

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Background: Since 2021, an international collaboration has emerged between two research teams working on compassionate community projects in Belgium and Canada. Both teams were involved in action-research projects that aimed to co-design, implement, and evaluate two compassionate communities in each country. Those two projects took place over the same period (2018-2023), used similar data collection methods (e.g. observations, interviews and group discussions), and both focused on civic and community engagement in serious illness, end-of-life, loss, and grief. This presentation will focus on comparing the development processes, community engagement dynamics and outcomes of compassionate communities in Belgium and Canada, thereby stimulating international cross-learning.

Objectives: The 8th PHPCI Conference seems to be an ideal opportunity to offer a cross-cultural perspective on two Belgian and two Canadian compassionate communities. The objectives are to comparatively describe and reflect on community development processes and community engagement dynamics to understand how these initiatives can be adapted and implemented effectively in diverse urban, rural, cultural, or socio-economic contexts.

Design & Methods: Two action-research projects were conducted independently in Canada and Belgium over 5 years. Data were collected and analyzed using an ethnographic method (Canada) and a convergent parallel mixed-method process and outcome evaluation (Belgium). To draw cross-cultural conclusions, we compared specific results relating to initiation, local contexts, community development and engagement processes (e.g. funding source, stakeholders involvement, meetings structures, strategies to reach and engage communities).

Results: Insights from this cross-cultural comparison provide a nuanced understanding of the dynamics and outcomes of research initiatives that bridge academia and community development. We observed that the source of funding, community leadership, and a sense of ownership have an important impact on outcomes (e.g. type of implemented projects, populations reached), perceived changes (e.g., an increased sense of community belonging and social connectivity), and sustainability.

Conclusion: Our findings contribute to narrowing the knowledge gaps on how differences in funding and coordination influence the scope of actions, community engagement processes and sustainability, suggesting the need for further in-depth cross-cultural comparisons.

ID: 275

Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, The value of death

Keywords: anthropology, public health approaches to death and dying, relationship to death, theory, transformations

How culture shapes the relationship to death: towards an anthropological theory to track social and cultural transformations in public health approaches to death and dying

Émilie Lessard

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Background: In 2022, *The Lancet Commission on the Value of Death* sets a research agenda that puts forward the concept of 'realistic utopia', calling for a radical paradigm shift regarding the relationship to death. Public Health Palliative Care assumes this shift can be achieved through socio-cultural transformations embedded in five principles: 1) acting on social determinants of dying, death and grief; 2) promoting a social model in which dying is seen as a social, relational and spiritual process; 3) building support networks for caregivers, the dying and the bereaved; 4) breaking the death taboo through storytelling about ordinary death and grief; 5) recognizing the value of death. Although the aim is to bring about socio-cultural transformations in the way we live, care, die and grieve, we still know very little about whether such initiatives achieve this goal because it is undertheorized.

Objectives: The objectives are to situate, within an explanatory model, the sociocultural forces that are transforming the Western relationship to death over time, and to demonstrate how this model can serve as an overarching theoretical framework encompassing the five principles to better capture socio-cultural transformations.

Design & Method: As part of a doctoral thesis completed in 2021, an explanatory model of the transformations in the Western relationship to death was developed to better understand contemporary experiences of death and dying. Grounded in anthropology, a transdisciplinary literature review was conducted to develop a theoretical model of the evolutionary process of the human relationship to death.

Results: The model describes the neurobiological and socio-cultural foundations of the relationship to death as human universal across societies, cultures, and time. Built on these foundations, the model explains, using a social ecology framework, the production mechanisms of five immortality regimes in Western civilizations (Ancestral, Divine, Christian, Scientific and Postmortal). These coexisting regimes, as foundational and structural determinants of death, dying and grief, have a major influence on the contemporary attitudes, beliefs, meaning and value attributed to death.

Conclusion: This theoretical model offers an in-depth understanding of the socio-cultural forces that drive the relationship to death, thus, holds great potential for tracking the socio-cultural transformations that public health approaches to death and dying hope to achieve.

ID: 276

Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: compassionate community, evaluation, resources, tools

The Compassionate Community Evaluation Guide: a tool to increase evaluation capacity

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Background: Compassionate Communities can be challenging to evaluate as a complex health and social intervention. This is particularly true for community-based or non-profit organizations, whose resources and assessment capabilities vary widely. A guide has been developed to increase evaluation capacities for such organizations by providing them with a step-by-step checklist and the necessary tools for their work. The Compassionate Community Evaluation Guide has been designed to support the self-assessment of an individual activity, a project, or a program within an initiative.

Objectives: The presentation aims to demonstrate how to use the Guide to create and administer evaluation plans for compassionate communities' initiatives at different development stages.

Design & Methods: Over five years, the Pan-Canadian Compassionate Communities Evaluation Project, which is a collective effort between Pallium Canada, BC Centre for Palliative Care, Hospice Palliative Care Ontario and leaders dedicated to palliative and end-of-life care, has resulted in the publication of an evaluation guide for compassionate community initiatives. The development process for the Guide included various consultations with community members working within the Compassionate Community space, or anyone aiming to support caregivers, those grieving and/or dealing with a serious illness. These consultations influenced the creation of a Canadian definition, stages of development, evaluation framework and, ultimately, the Guide. Through an academic-community partnership, the self-funded evaluation guide and associated tools have been pilot-tested before the release of the final version.

Results: As a result, the Guide shows, step by step, how to develop an evaluation plan and what to look out for in each development stage. It provides an evaluation framework promoting the use of common evaluation questions and measures across different Compassionate Community's initiatives and stages of development. The Guide also provides evaluation tools, resources and printable materials to support evaluation capacity at different levels.

Conclusion: The Guide is a free ready-to-use resource for anyone who wants to measure and track the progress of their Compassionate Community's initiative seamlessly, regardless of their level of knowledge and experience of evaluation methods.

ID: 277
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving

Keywords: Ethnicity, equity, cancer, pain, observational cohort study

Ethnic disparities in rates of opioid prescribing for cancer pain and impact on health service use in the UK: Findings from an observational cohort study

Jonathan Koffman[1], *Sophie Law-Clucas*[1], *Sabrina Bajwah*[2], *Gemma Clarke*[3], *Rashmi Kumar*[2], *Martin Gilliford*[2], *Stephen Barclay*[4], *Emeka Chukwusa*[2]

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Background: Relief from cancer pain is a public health issue and a human right. Opioids are effective in managing pain and are a population-based quality marker for end-of-life care. Ethnic inequity is evident in the receipt, experiences and outcomes of end-of-life care. No UK research has examined if the prescribing of opioids varies by ethnic group.

Aim: To examine trends in opioid prescribing patterns regarding patient ethnicity during the last six months of life and describe its association with health service.

Design: Observational cohort study.

Methods: 232329 adult patients aged ⩾18 years in England diagnosed with cancer who died between 2011 and 2021 using linked data from the Clinical Practice Research Database, Hospital Episode Statistics and Office for National Statistics. Opioid prescription rates during the last 6 months of life were described. Poisson regression models fitted using Generalised Estimating Equations examined associations between opioid prescribing and ethnicity and health service use. The model was adjusted for patients' sociodemographic and clinical characteristics. The strength of association was described using adjusted rate ratios (aRR) and 95% confidence intervals (95% CI).

Results: The most common cancers were lung (56779, 24.4%) colorectal (43524, 18.7%) and breast cancer (42710, 18.4%). Less than half (97734, 42.1%) of patients received at least one opioid prescription during the last 6 months of life. Compared to the White British reference population the aRRs of opioid prescribing were markedly lower for patients from minority ethnic communities - Black aRR 0.87 (95% CI 0.78–0.98), South Asian aRR 0.86 (95% CI 0.77–0.96), mixed ethnicity aRR 0.75 (95% CI 0.61–0.91) and 'other' ethnicity aRR 0.82 (95% CI 0.70-0.97). Rates of emergency department attendance were commensurately higher for patients from minority ethnic communities than the reference group - Black aRR 1.08 (95% CI 1.03-1.13), South Asian aRR 1.12 (95% CI 1.07 – 1.17) mixed ethnicity aRR 1.13 (95% CI 1.01 -1.26) and 'other' ethnicity aRR 1.04 (95% CI0. 95-1.13).

Conclusions: We identify novel public health findings. Disparities exist in rates of opioid prescribing among minority ethnic patients and differences in health service use, both with potential negative impacts on patient quality of life. Future research is needed to explore explanations of why differences exist leading to a path to patient benefit.

ID: 278

Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: process evaluation; outcome evaluation; compassionate communities; advance care planning

Measuring the effectiveness of a Compassionate Communities initiative to raise public awareness of palliative care and advance care planning: an evaluation framework

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Background: Raising awareness of palliative care and advance care planning is essential to better prepare people for living with serious illness, dying, caregiving and grieving. We undertook a multi-year, multi-sectoral Compassionate Communities initiative to increase public awareness and understanding of palliative care and advance care planning. Public education tools were adapted to our local context and implemented in collaboration with community partners.

Objectives: To develop an evaluation framework for: 1) determining program effectiveness in raising public awareness of palliative care and advance care planning, and 2) contributing to best practice and knowledge on evaluating Compassionate Communities public awareness initiatives.

Design: Program development and implementation

Methods: We reviewed the literature to identify relevant framework(s) to guide our evaluation. Key informant interviews were held with stakeholders to solicit feedback on the selected evaluation framework(s) and proposed measures.

Results: A logic model was developed to synthesize the goals, inputs, audience, activities, outputs, process measures and outcome measures for the program. We selected the Healthy End of Life Program (HELP) Evaluation Framework to guide our process evaluation, based on its public health palliative care approach to evaluation, health promotion principles, and community development. We structured our outcome evaluation around the Australia Palliative Care Evaluation Framework to capture impacts on 'consumers', 'providers', and the 'broader care delivery system'. Outcome measures were adopted or adapted from validated tools where available and appropriate; some new measures were developed to assess domains lacking validated tools. Data collection is proving feasible and meaningful: to date, our process measures indicate we have created change in six of the eight HELP domains (People, Programs, Participation, Practice & Practitioners, Place, Partnerships); outcome data collection has just begun, but preliminary data indicate our tools are improving knowledge of, and attitudes, toward palliative care and advance care planning.

Conclusion: Whereas the evaluation of Compassionate Communities initiatives is a relatively new area of study, we hope this evaluation framework proves useful to others undertaking similar public awareness initiatives.

Funding provided by Government of Alberta. Opinions do not necessarily reflect the position of the Alberta government.

ID: 280

Abstract Type: Oral presentation

Topics: Policy and advocacy

Keywords: Advance care planning, national working group, self-determination, autonomy

Implementation of advance care planning (ACP) in Switzerland: Strategy of a national working group

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Idea: «Where do you stand with your advance care planning (ACP)?» This question is still rarely asked among family and friends. The national working group (ACP WG), commissioned by the Federal Council and led by the Federal Office of Public Health (FOPH) and the Swiss Academy of Medical Sciences (SAMS), is working to ensure that this becomes more common.

ACP is a process that is open to everyone - not just people at the end of life. Through ACP, individuals reflect on their personal values, wishes, and expectations regarding treatment and care in the event of illness or accident, thereby enhancing self-determination. There are different ways of dealing with the topic. The aim of normalizing ACP does not mean imposing a norm: there is no «right or wrong» in dealing with these sensitive issues.

Implementation: The task of the national ACP working group is to steer the implementation of ACP measures to strengthen awareness, accessibility and quality of ACP and set key priorities.

Lessons Learned: The ACP WG published the «Roadmap for the implementation of advance care planning (ACP) in Switzerland» in March 2023, which outlines 12 recommendations. They cover four main areas:

- Measures to ensure that ACP becomes a normal part in life for all people who want it, regardless of age, place of living, phase in life, origin, health literacy and health condition;
- Assistance in appointing an authorized representative and in reflecting about unforeseeable and/or complex medical events, as well as dying and death;
- Supporting healthcare professionals in addressing ACP by strengthening their communication and methodological skills;
- Improving the quality and accessibility of documentation and the framework conditions for the remuneration of ACP services.

The roadmap forms the basis for concrete projects to be implemented in the coming years. The challenge and at the same time the strength of the national initiative lies in the networking and cooperation with a large number of independent administrative, scientific and political structures. The aim is to continuously involve all the stakeholders at different levels and secure their support of.

ID: 281
Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: Caring Community, Compassionate Community, Compassionate City, Compassion

Caring Community Köln – lessons learnt so far

Karin Ohler[1], *Birgit Weihrauch*[2], *Sabine Eichberg*[3], *Anne Kreische*[3], *Julia Strupp*[4], *Raymond Voltz*[4]

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Idea: The aim of Caring Community Köln (CCK) is to promote skills relating to the end of life and thus strengthen civil society in dealing with serious illness, dying, death and grief. In 2016, the structure of a Caring Community for the city of Cologne with one million inhabitants was thought through for a research proposal and implemented despite rejection by the Palliative and Hospice Network Cologne e.V. and the City of Cologne.

Realisation: The official start took place in 2020 by the Mayor of Cologne. This was preceded by intensive discussions with organisations from urban society and local politics. Over 35 institutions and many more individuals from Cologne are now involved, including those involved in palliative and hospice care, as well as non-profit organisations, business associations and companies such as banks and insurance companies.

The City of Cologne is a central partner of the initiative with its responsibility to provide public services of general interest and to promote public health - also as a member of the Healthy Cities Network. A steering group, the round table, four topic-related working groups and the coordination office have been established so far. While the round Table serves the participation of urban society, the building of consensus and the networking oft he stakeholders, the steering Group is responsible for conceptualisation and process ma-nagement. The coordination office is the central point of contact for committed and interested parties.

In addition to the working groups - Grief in the Workplace, Children & Young People, Care and Care City Plan - projects such as the *Buddy-Project for the seriously ill and their relatives*, LAUT: *last aiders at the workplace for a sensitive approach to dying, death and bereavement* or the Cologne *Death Café* are bundled and implemented under the umbrella of the CCK. Regular dialogue with citizens takes place in citizens' forums.

Conclusions: CCK can contribute initial experiences to the national and international discussion: Is a top-down or bottom-up approach or a combination needed? Which structures lead to a permanent anchoring in urban society? How can transparent and target-orientated cooperation between all stakeholders be achieved, especially with those outside palliative and hospice structures? How can – in some cases new – approa-ches be created to increase death literacy, for example through schools, workplaces or even the (carnival) clubs?

ID: 282

Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving

Keywords: end-of-life, preferences, ACP, communication, advance directive, population, survey

End-of-life preferences among different forms of engagement in advance care planning

Carmen Borrat-Besson[1], *Sarah Vilpert*[2], *Maud Wieczorek*[2], *Clément Meier*[2,1], *Robert Reinecke*[1], *Ralf J. Jox*[3,4], *Gian Domenico Borasio*[4], *Jürgen Maurer*[2]

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Background: Advance care planning (ACP) is the process of helping adults understand and share their personal values, life goals, and preferences for medical care, anticipating future decisional incapacity and documenting their preferences in advance directive (AD). While much research has been done on AD holders' medical preferences, few studies have considered non-medical preferences or have examined the preferences related to other engagement levels in the ACP process (e.g., discussing preferences without making an AD).

Objective: To examine the relationship between individuals' engagement in the ACP process and the importance attached to different medical and non-medical end-of-life (EOL) aspects in a representative sample of the Swiss population aged 55+.

Method: Swiss respondents (n=2063) to the Survey on Health, Aging, and Retirement in Europe (SHARE) rated in 2016 the importance of 23 EOL aspects (0='not important' or 'not so important' and 1='important' or 'very important'). Respondents were also asked whether they discussed their EOL wishes (0='no' and 1='yes') and had an AD (0='no' and 1='yes'). Engagement in the ACP process was derived from these two last variables (1=neither discussed nor made an AD, 2=only discussed, 3=only made an AD, 4=discussed and made an AD). Associations were examined using multivariable logistic regression models, controlling for sociodemographic, regional and health covariates.

Results: Overall, 44% of participants have neither discussed their EOL wishes nor written an AD, while 32% have only discussed their EOL wishes without writing an AD, and 6% have only written an AD but not discussed their EOL wishes. Only 18% discussed their EOL wishes and wrote an AD. Most participants consider many different EOL aspects important, with significant variations across their engagement in the ACP process. Specifically, participants who discussed their EOL wishes and/or have an AD were more likely to find it important to prepare for the EOL and decide on related aspects. Further, among respondents who discussed their EOL wishes, those without an AD were more likely to find psychosocial aspects important than those with an AD.

Conclusion: Engagement in the ACP process correlates with the importance attached to some EOL aspects. Our results further suggest that better highlighting the non-medical aspects included in ACP could motivate a greater number of individuals to actively prepare for their EOL.

ID: 284

Abstract Type: Poster

Topics: Educational approaches

Keywords: young adults, palliative care, knowledge, perception, campaigns

Destigmatising palliative care within the peer group of young adults: Systematic review and ideas for interventions in the context of public health

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Background: As a result of demographic change, chronic and oncological diseases are becoming increasingly important in the context of public health. Palliative care plays a crucial role in maintaining the quality of life of those affected. International guidelines call for access to palliative care not only for the elderly but also for younger people facing severe illness. It is likely that palliative care will become increasingly important for them. Little is known about young adults' knowledge and perceptions of palliative care.

Objectives and design: This work aims at assessing the knowledge and perceptions of palliative care among young adults' (age 18-24), with the results serving as a basis for the theoretical development of interventions and campaigns promoting and destigmatising palliative care within this age group. We conducted a systematic review and made use of the "Intervention Mapping" protocol.

Methods: Exclusion and inclusion criteria were developed using the PICOS progress. Literature was researched within Medline (via Pubmed), google scholar and Web of Science. A search string was developed and refined for all three databases. Duplicates were excluded using Mendeley. The literature was independently screened by two researchers. Narrative synthesis was used to answer the main research question. The six steps of the Intervention Mapping Protocol were followed to theoretically develop interventions and campaigns.

Results: Initially, 1,766 papers were found. After the removal of duplicates and screening 60 studies were included. Their study design was mainly cross-sectional (68%). Young adults know of the term palliative care, however, they do not have a nuanced knowledge. They associate palliative care with death and dying and see its relevance at the end of life. They perceive palliative care to be a medical discipline primarily for the elderly. Young adults demand participation within the planning of interventions to destigmatise palliative care. They demand to receive information on digital devices via the internet. Interventions should entail evidence-based methods of behavioral change such as "cooperative learning" or "interpersonal contact".

Conclusion: Young adults are a crucial peer group in order to destigmatise palliative care and facilitate access to palliative care in the future. Interventions should entail multiple components: Transfer of knowledge, interaction with affected peers and dissemination of information within the digital space.

ID: 285

Abstract Type: Oral presentation

Topics: Relationships and connection, Social and structural determinants of death dying and grieving

Keywords: Advance care planning, end of life care, decision making capacity, dementia, relationships

Reconstructing the presumed will of people who no longer have medical decision-making capacity in order to promote their autonomy in future treatment decisions: a discursive and conversation analytic study of naturalistic data

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Lausanne University Hospital, Switzerland

Background: Advance care planning (ACP) is effective in promoting care that is coherent with one's wishes should they lose decision making capacity (DMC). ACP can be conducted 'by proxy' for people lacking DMC. This involves health care proxies reconstituting the person's presumed will based on their knowledge of the person, their life and values in order to provide them with access to ACP and thus end of life care that is coherent with their wishes. ACP by proxy models are new and little is known about the ways in which a person's presumed will is elicited in these circumstances.

Objectives: To investigate ways in which ACP by proxy discussions are conducted and the ways in which health care proxies, physicians and ACP facilitators reconstitute a person's presumed will.

Design: mixed methods single arm intervention pilot study.

Methods: 11 ACP by proxy encounters between ACP facilitators, health care proxies and treating physicians were audio-recorded. Audio files were transcribed verbatim and selected extracts which were used for the discursive and conversational analyses were transcribed according to the Jeffersonian method.

Results: Explorations of people lacking medical DMC's presumed wills draw upon repertoires of 'closeness' and 'connection' to the person, particularly from the health care proxy in relation to their 'previous' knowledge of the person, and from heath professionals in relation to their 'current' knowledge of the resident. These notions are corroborated and compared to work up notions of the residents' current presumed will. Numerous discursive 'tools' used in this reconstruction will be presented.

Conclusions: Discursive and conversational analyses provide important insights for training health professionals to explore the presumed will of patients who no longer have DMC and thus draw upon relationships with loved ones and health professionals to improve social and structural determinants of promoting care (inc. end of life) that is consistent with their wishes.

ID: 286

Abstract Type: Oral presentation

Topics: Educational approaches

Keywords: Proactive end-of-life communication, nursing students, learning activity, gamification

We are all mortals – Undergraduate nursing students' reflections following a seminar focused on proactive end-of-life communication

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Background: Prior research show that nursing students may experience dying as frightening, and feel uncertain and unprepared to communicate with patients nearing death and their families. An interactive learning activity was therefore created, including preparatory self-reflection on end-of-life preferences using the Swedish adaptation of the GoWish cards – the DöBra cards – followed by a seminar with group discussions.

Objectives: To explore nursing students' reflections after a learning activity focusing on proactive end-of-life communication.

Design: Inductive, qualitative study.

Methods: Following the seminar, students had an optional written assignment to answer three reflective questions about their learning, experiences, and main takeaways. Free-text answers from 160 consenting students of three course iterations were analyzed using Interpretive Description.

Results: While feeling unfamiliar at first, the task of reflecting on their own death and themselves as mortals was rewarding and valuable to students. They especially appreciated the opportunity to reflect on how their end-of-life values and preferences may change over their life-course. Group discussions facilitated students' acknowledgement of the importance of proactive end-of-life conversations to understand others' preferences, thus increasing the likelihood of providing person-centered end-of-life care. The most prevalent 'takeaway' mentioned was gaining the courage to talk about death and dying in the future. Students emphasized that the seminar helped them obtain knowledge and skills in engaging in end-of-life conversations that they would make use of both as professionals and in their private lives.

Conclusion: In this first study to report the use of DöBra/Go Wish cards in nursing education, we argue in favor of using a 'first-person perspective' when engaging students in learning about proactive end-of-life communication. Designing activities where students are encouraged to 'do knowledge' by actively engaging with the subject rather than simply 'gain knowledge' should be further considered in education on end-of-life communication. For this, faculty need to carefully consider how to create safe learning environments. Various forms of individual and group reflection lowered the threshold for students to engage in future end-of-life communication, both as professional nurses and private persons – thus recognizing the fact that we are all mortals.

ID: 287

Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: LGBTQ+, social support, compassionate communities, end-of-life, action research

Intergenerational conversations about LGBTQ+ needs at the end-of-life – reflections from Sweden

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Background: Sexual and gender minority populations (LGBTQ+) may have specific experiences and concerns regarding aging, dying, death, and loss. For example, in Sweden, older LGBTQ+

people have lived in times when their identities were criminalized and pathologized, and experiences from the HIV/AIDS pandemic may influence their concerns about end-of-life (EoL) care. Furthermore, there are few intergenerational LGBTQ+ spaces to exchange experiences and build community. Therefore, researchers and community organizations partnered to develop "DöBra Rainbow Cafés" by and for LGBTQ+ people to engage with EoL-issues. DöBra is a Swedish pun, literally meaning dying well, figuratively meaning awesome.

Objectives: To investigate the development process of the DöBra Rainbow Cafés and experiences of participating in them.

Design: Qualitative action research.

Methods: Six cafés were held in 2022–23 (with 5 community partners and 81 café-attendees). Cafés were developed iteratively. Conversations were facilitated by open-ended questions and arts-based activities. Qualitative data consists of notes from reflective meetings held after each café and follow-up interviews with 26 participants (5 partners, 21 attendees, age 25-87) to date, subject to inductive analysis.

Results: Participants described the cafés as a space to discuss issues related to aging, dying, death, and loss without a need to consider the dominant heteronormative societal discourse. While participants raised some EoL-care related concerns that may be relevant regardless of sexuality or gender identity, they also expressed concerns about not being able to live authentically at the EoL. While older people drew on past experiences to explain this (e.g., being discriminated), younger people referred to increasing negative LGBTQ+ sentiments globally. The iterative café development illustrated the disparate needs of this diverse group. E.g., while the first café was intergenerational and invited anyone across the LGBTQ+ spectrum, community partners noted that lesbian women and transgender people were underrepresented. Therefore, 2 specifically trans-cafés were held and 1 café for older lesbians.

Conclusion: Findings indicate a need for safer spaces where LGBTQ+ people can discuss EoL-related concerns and find social support. Findings may help sensitize EoL-care staff to LGBTQ+ perspectives.

Conflict of interest: The authors report no conflict of interest.

Funding: FORTE: Grant number 2021-01956

ID: 288

Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Policy and advocacy

Keywords: LGBTQ+, death system, queer theory, end-of-life

Queering the death system – perspectives from LGBTQ+ people in Sweden

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Background: People belonging to sexual and gender minorities (LGBTQ+) have been and still are structurally marginalized, with a global increase of negative LGBTQ+ sentiments. Research finds that structural marginalization may affect LGBTQ+ people's experiences and concerns regarding dying, death, loss, and care at the end-of-life (EoL). However, the body of knowledge about this is scarce as research is often biased towards heteronormative relationships.

Objectives: To explore ways in which LGBTQ+ people in Sweden deal with issues related to dying, death, loss, and EoL-care.

Design: Qualitative interview study.

Methods: Participants were recruited through DöBra Rainbow Cafés, i.e. meeting places for and by LGBTQ+ people to engage with EoL-issues held in partnership with local LGBTQ+ organizations. To date, 26 interviews have been held (age 25-87). Kastenbaum's death system is used as a basis for analysis. The death system concept describes society's ways of dealing with dying, death, loss, and EoL-care as "functions" over time (from preventing death to consolidation after death) and "components" for each function (i.e. people, times, places, and symbols/objects).

Results: Participants described encountering friction and conflict with society's heteronormative ways of dealing with dying, death, loss, and EoL-care. For example, friction and conflict between heteronormative healthcare services and the wishes of LGBTQ+ patients, between biological families and LGBTQ+ communities, and between religion and LGBTQ+ lifestyles. Ways in which participants dealt with such friction and conflict was conceptualized as "queering the death system". For example, participants described creating queer caring networks and holding LGBTQ+ memorials. Some modified death-related ceremonies and rituals through art and LGBTQ+ symbolism. Certain conflicts with healthcare services and biological families seemed hard to resolve due to power structures enforced by heteronormative rules, regulations, and laws.

Conclusion: Normative ways of understanding the death system exclude LGBTQ+ ways of dealing with EoL-issues. Drawing on these findings and research with other structurally marginalized people (e.g., indigenous people), we call for queering the death system to develop public health palliative care initiatives that are inclusive of anyone living outside the norm.

Conflict of interest: The authors report no conflict of interest.

Funding: FORTE: Grant number 2021-01956

ID: 289
Abstract Type: Oral presentation

Topics: Policy and advocacy, Educational approaches

Keywords: Palliative care, Public awareness campaigns, Audience reception research, Focus groups, Public perceptions, Communication, Social environment

"Why should I care?": an audience reception study of public awareness campaigns on palliative care

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Background: Public awareness campaigns on palliative care (PC) aim to combat limited knowledge and negative perceptions of PC. However, little is known on their public reception.

Objectives: To examine how existing public campaigns on PC are interpreted, evaluated and allocated meaning by members of the general public, and how campaign materials and surrounding conversations affect prior perceptions of PC.

Design and methods: Three public campaigns (spread in Flanders or the Netherlands between 2020-2023) were discussed in ten focus groups. Participants (n=65) were recruited via a sequential maximum variation sampling strategy. Conversations were analyzed using the Multidimensional Audience Reception Model.

Results: Our study revealed large differences between campaigns concerning overall appeal, clarity of communication, attitudinal responses toward the perceived message and its delivery. People with personal experience surrounding serious illness were generally more open towards campaign messages, while a sense of personal relevance was lacking for persons without these experiences. Conversations surrounding the campaign materials revealed a dominant perception of PC as end-of-life care provided mainly in hospitals to severely ill, bedridden persons. Campaigns that informed on PC through the perspectives of persons with serious illness, while portraying them in their strength, were more positively evaluated and effective in changing prior perceptions. Conversely, materials that neglected the patient's voice and focused on 'PC enabling small joys despite serious illness' generally fortified prior perceptions and were often rejected. Further, a preference for more emphasis on the broader social context surrounding the patient was recurrently expressed. Lastly, conversations in themselves proved to be a valuable tool to positively influence understandings and openness towards PC, and organizing local conversation events was repeatedly suggested.

Conclusion: Diversified strategies, optimizing a sense of personal relevance for the target audience, are needed to improve public understanding and engagement with PC. Beyond the broad dissemination of succinct messages on PC, more opportunities for meaningful dialogues within local communities need to be created. Destigmatizing PC also involves destigmatizing persons with serious illness and representing them in active and resilient positions is vital to this.

Conflict of interest: None.

ID: 291

Abstract Type: Workshop

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: schools, children, compassioniate communities, education, support

Building on evidence, experiences, and mutual reflections to develop Compassionate Schools: a practical workshop

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Target Audience: This workshop is for anyone involved or interested in developing Compassionate Schools, that is schools which address the educational and support needs of its community at times of serious illness, caregiving, death, and bereavement.

Learning Objectives: By the end of the workshop, participants will have:

1. Heard about the development of Compassionate Schools, including engagement processes and possible actions, as generated via the Compassionate Schools European Learning Network.
2. Reflected on how they would develop and facilitate their own Compassionate School, from their personal and professional perspectives.
3. Engaged in critical discussion around the commonalities and essentialities in developing Compassionate Schools. This includes increasing awareness of and reflection on the availability and need for resources, readiness, inclusion of relevant partners, and the facilitation methods required to develop a Compassionate School.

Compassionate Schools are places which are attentive to and actively address the educational and support needs of its community (students, staff, and families) at times of serious illness, caregiving, death, and bereavement. They recognise that these events are universal experiences that have an individual and collective impact and, as such, warrant attention: which today is not always the case. Through a series of actions, preventive measures, and educational activities, Compassionate Schools aim to meaningfully integrate such experiences into school life. Furthermore, by providing school communities with the proficiency to respond to such events, valuable skills are gained that both students and staff can use throughout their lives. This interactive workshop will introduce participants to the variety of possible actions that can be facilitated in and with schools, sharing learning from the Compassionate Schools European Learning Network. Participants will then be supported to engage in an in-depth discussion on steps they can take to develop their own Compassionate School, drawing on their local context and own positioning. Finally, participants will be provided with an overview of the commonalities and essentialities in the development of Compassionate Schools, exploring key issues around resources, readiness, partnership working, leadership, and the range of facilitation methods required to develop a whole schools approach to caregiving, serious illness, death, and bereavement.

ID: 293

Abstract Type: Oral presentation

Topics: Relationships and connection, Social and structural determinants of death dying and grieving

Keywords: homelessness, palliative care, education, training

Developing the Intervention to optiMise Palliative caRe for peOple with liVed Experience of homelessness (IMPROVE)

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Background: People experiencing homelessness have high rates of long-term conditions at a young age and are at high risk of dying young. In the UK many people with complex and advanced physical and mental health problems are living in homeless hostels, and rarely have access to palliative care. Supporting palliative care needs among this group requires a multi-disciplinary trauma informed response, which can be hard to achieve.

Objectives: to identify the educational needs of people from a range of different backgrounds, to produce content for IMPROVE which aims to facilitate local, multiprofessional communities of practice around palliative care and homelessness.

Design: Review of existing materials, research and consultation with inclusion health and palliative care and homelessness experts.

Methods: Desk based review of findings of previous research and educational materials and consultation with key stakeholders to identify the components of an educational intervention, for people from a range of professional groups, when supporting people experiencing homelessness who have advanced ill health.

Results: Topics identified included: understanding the causes, health and social care issues affecting people experiencing homelessness, the context of temporary accommodation as a place of care, complex trauma, communication, frailty and neurodiversity, addiction and working with change resistant drinkers, mental capacity assessment, palliative and end of life care planning, bereavement support. These formed the basis of IMPROVE, which contains videos and resources to deliver 8 online sessions supporting the development of local, multi professional communities of practice addressing palliative care and homelessness.

Conclusion: To improve support for people experiencing homelessness who may have palliative care needs, a broader approach, accounting for marginalization and trauma, is necessary. IMPROVE provides a mechanism for facilitating joined up approaches by making connections and providing an introduction to the range of inclusion health and homelessness related topics that are necessary to provide trauma informed, multi professional care towards the end of life for this population. Online communities can help to address the inequity that exists in palliative care access for people experiencing homelessness. IMPROVE has been piloted in the UK with promising results.

Conflict of interest: None

Funding: Funded by The Oak Foundation and Marie Curie. Supported by NHSE

ID: 294
Abstract Type: Poster

Topics: Research methods, Educational approaches

Keywords: Comfort care order set, end-of-life medication, prescribing

Comfort care order sets in an ambulatory setting

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According to two Swiss surveys, many elderly people would like to die at home. Reality is different and most die in hospital. There are numerous reasons for this discrepancy, notably the lack of end-of-life drugs available at home. General practitioners may be unfamiliar with prescribing and administering the “Four Essential Drugs Needed for Quality Care of the Dying,” which include analgesics, anti-secretory and/or sedatives. Trained and available home care teams are needed to support patients and provide active palliative care. General practitioners may not have palliative training, and palliative care team intervention may not always be possible/necessary. To assist these physicians, a comfort care order set was developed in conjunction with palliative care training. Order sets have proven to reassure, guide clinicians and prevent prescribing errors, thereby improving patient safety.

Project: Computerized comfort care order sets for common end-of-life symptoms such as pain, anxiety, agitation, shortness of breath, and death rattle were created by an interdisciplinary group of geriatricians and palliative care specialists. Goals include preventing medication errors, promoting patient safety, and facilitating accurate end-of-life prescribing. Order sets include established protocols, doses, and non-drug interventions. Physicians can select the appropriate medication from a recommended list based on symptoms and efficiently change the dose/frequency. Once signed, medications appear in the patient’s record, also visible when the patient is admitted. It can also automatically generate a prescription for the pharmacy.

Evaluation: A questionnaire will be sent to physicians using these comfort care order sets to assess their experience in prescribing end-of-life medications before and 3 months after implementation. A short training course in palliative care will be offered. Results will be analyzed based on improvement in physician comfort with prescribing and ease of prescribing the system’s integrated order sets. Comparison of opioid prescribing and documentation errors pre and post.

Our hypothesis is that comfort care order sets will increase primary care physicians’ comfort level with prescribing of essential medications for end-of-life care at home and improve anticipation of emergency situations. These comfort care order sets may contribute to patient safety in general and may be extended to other settings, such as general internal medicine wards.

ID: 295

Abstract Type: Poster

Topics: Relationships and connection

Keywords: Patient comfort, Serious illness conversations, Communication, Patient-physician relationship, Factorial survey

Communication styles that bring comfort during serious illness conversations: A Swiss wide study

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Background: Conversations about serious illness frequently cause discomfort among patients nearing the end of life. This unease can hinder their comprehension of prognosis and treatment choices, potentially affecting the decisions they make and their overall well-being. Identifying how physicians might reduce that discomfort could improve care.

Objective: This study investigated which physician communication styles and characteristics are perceived as comforting in physician-patient serious illness conversations.

Design: Nationwide online factorial survey study.

Methods: The online survey was provided in German, French, and Italian. A total of 1572 individuals from the Swiss public (51.4% women) whose ages ranged from 16 to 94 years participated. Each participant evaluated 5 out of 1000 distinct vignettes depicting interactions between physicians and cancer patients receiving terminal prognoses. In these interactions, we systematically manipulated 11 attributes: experience of the physician, sex of physician, sex of the patient, age of the patient, prior relationship to physician, clarity of information, self-disclosure, physician taking time, recommendation, expression of sadness, and continuity of care. Participants evaluated their comfort level with the physician described in the five vignettes.

Results: Clarity of information delivery ($\beta=2.13$, $p<.01$), taking enough time ($\beta=2.00$, $p<.01$), and mentioning continuity of care ($\beta=1.27$, $p<.01$) were the strongest predictors of comfort. Prior physician-patient relationship significantly increased comfort, with a more prolonged relationship being even more comforting ($p<.01$). Physician self-disclosure ($\beta=0.41$, $p<.01$) and physician expression of sadness, including tearing up ($\beta=0.46$, $p<.01$; $\beta=0.58$, $p<.01$) were also found to increase comfort. Failing to provide reasons for recommendations decreased comfort ($\beta=-0.24$, $p<.01$). Recommendations based on experience did not influence comfort, but if based on patient preference, increased it ($\beta=0.30$, $p<.01$).

Conclusion: Taking time, providing clear information, and ensuring continuity of care are crucial for improving comfort during serious illness conversations. Also relevant for increasing comfort levels are the expression of sadness, the physician's self-disclosure of personal information, and establishing a prior short or long relationship with the patient.

ID: 296

Abstract Type: Oral presentation

Topics: Policy and advocacy

Keywords: Palliative Care, Health services research, End of life, Health economics, Cost components

Keeping health care affordable - which health care components drive the cost of end of life care in hospitals?

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Background: Literature highlights the benefits of specialist palliative care (PC) programs in enhancing end-of-life care quality, yet research on PC's economic aspects, particularly in Europe, is scarce. The OECD reports significant financial strain on the healthcare systems of the world's wealthiest countries, with Swiss healthcare spending increasing by about 2% annually since 1990. This economic perspective is crucial as substantial healthcare costs often accumulate in the last months of life. Existing cost studies, primarily

from the U.S., provide mixed results and lack detailed analyses of cost components -such as pharmacy, materials, laboratory, room, catering, patient management, physician, nursing, therapy, and social counseling- in PC especially from studies with a control group like usual care (UC) patients.

Objectives: This study shows the costs components of patients who deceased in a tertiary hospital comparing patients who received PC and UC.

Design: Observational retrospective data analyses of administrative hospital data.

Methods: Our research involved reviewing medical records of 3'586 patients, who died in a tertiary hospital between January 2016 and December 2022 focusing on health-related and economic data from the last hospitalization. Crude cost data with mean and standard deviation were compared between PC and UC group using linear regression with robust standard error. We used bootstrapping to correct for bias and calculate 95% confidence intervals. Cost data were adjusted using inverse probability weighting based on propensity scores.

Results: Our preliminary results show that costs directly related to patient care -such as those for nursing, therapy, and room- increase significantly for patients receiving specialist PC. Conversely, there is a significant reduction in costs associated with physician lead, medical intervention, medication, laboratory tests and materials, contributing to a lower total daily cost for PC patients compared to those receiving UC. Nevertheless, total costs per hospital stay rise due to longer length of stay of patient with PC likely due to challenges in transferring long-term patients to other facilities or home settings prior to death.

Conclusion: Even though hospitals have only few possibilities to balance quality and costs, one controlling instrument for hospitals might be an increasing implementation and promotion of PC not only for quality reasons, but also to allocate costs efficiently at the end of life.

ID: 297
Abstract Type: Oral presentation

Topics: Research methods

Keywords: adaptation, public health palliative care intervention, multi-setting, implementation science, ADAPT guidance

Adapting public health palliative care interventions to new settings using ADAPT guidance: the example of NavCare-EU

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Background: The recently published ADAPT guidance provides various approaches for adapting existing interventions to new contexts. We adapted a public health palliative care (PHPC) needs-based navigation intervention for older people with cancer experiencing declining health, called Nav-CARE, to six European countries using the ADAPT guidance. The literature to date, illustrating and reflecting on such systemic adaptation approaches of PHPC interventions, is extremely limited.

Aim: To describe the systematic adaptation process of Nav-Care EU across diverse settings following the ADAPT guidance. Moreover, we reflect on the use of the ADAPT guidance and its suggested frameworks and provide recommendations for others seeking to transfer public health palliative care interventions across settings.

Design: We used an iterative five-stage multimethod approach, using the ADAPT guidance and its recommended frameworks for conducting context analysis (CICI), guiding decision-making (MADI) and reporting (FRAME) on adaptations.

Methods: Both local adaptation teams and an international adaptation team have been established to conduct and evaluate the adaptation process. The international team synthesized and discussed data from adaptation reporting sheets, adapted intervention materials, semi-structured duo-interviews with implementation agents on implementation context, adapted training material and schedules, international adaptation team meeting minutes, context reporting sheets, and questionnaires on the composition and perceived importance of the local adaptation teams.

Results: We (1) identified core and discretionary components of the original intervention, (2) adapted implementation materials, (3) conducted a contextual analysis, (4) adapted the training for the implementation agents, and (5) conducted a feasibility review.

Conclusion: The ADAPT guidance provides both flexibility and guidance for systematic adaptations of PHPC interventions across settings. Determining core and discretionary components can be a qualitative way of assessing intervention's fidelity during adaptation of PHPC interventions across settings. Conducting a comprehensive contextual analysis, and involving both local and international adaptation teams safeguarded the intervention-context fit.

Funding: European Union, Horizon Europe (2022-2027)

ID: 299

Abstract Type: Oral presentation

Topics: Relationships and connection, Sustainability and planetary health

Keywords: Palliative Care, Home care, Primary Care, Sustainability, Community care

Rethinking palliative care from a sustainable perspective

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Catherine Dorogi, Sarah Leduc, Florence Payet
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This practical project is part of the need to rethink Palliative Care (PC) from a sustainable perspective. Our foundation currently offers specialist palliative care (SPC) in hospital and is recognized as a center of expertise: it receives patients, their families and relatives. Established in the heart of a small town, our foundation is characterized for its close links with the local population, making it easier to understand the specific needs of the context. It is currently engaged in a process aimed at expanding its range of support services. The project, which has a human dimension, promotes a community care approach, emphasizing collaboration with community health organizations and local health institutions to provide care centered on the specific needs of each patient. In this region, there is no access to first line specialized palliative care at home or in nursing home. The introduction of a new model aims to provide 1st line primary care directly at home and in nursing home by offering a 24/7 telephone hotline (for patients and staff) to respond concretely with field interventions in case of palliative emergency needs. The service will provide a full assessment, personalized medical treatment, coordination with existing teams and advanced technical care, all under the supervision of a medical and nursing team. For several years, health professionals and hospital management have been making clinical observations, which is supported by research into scientific and political findings. In order to adapt the project to the context, an analysis of resources was necessary. At the same time an assessment of barriers and facilitators was undertaken. Careful planning, proactive risk management and taking advantage of opportunities can ensure the success of such a pivotal initiative for the community. It remains essential to be agile and resilient in the face of challenges throughout the project. The sustainability of the Swiss healthcare system is being significantly challenged, highlighting the fact that medicine is based on a model of infinite progress, raising expectations that are oQen unrealistic, while the financial and human resources required are limited. This project to improve access to PC is designed to be implemented in the context of the evolution of the healthcare environment and the needs to support societal changes aimed at ensuring its sustainability

ID: 301

Abstract Type: Oral presentation

Topics: Educational approaches

Keywords: screening, tool, implementation, general palliative care, specialised palliative care

Deployment of a tool for identifying palliative care patients (ID-PALL) in a university hospital neurology and neurosurgery service

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Nadia Nouri Lalaoui, Davide Strambo,
Krystel Vasserot, Philip Larkin, Claudia Gamondi,
Fabienne Teike
Lausanne University Hospital, Switzerland

Background: Identifying patients requiring palliative care is a major public health concern in order to improve equitable access. ID-PALL is a validated instrument accompanied by recommendations for good practice that supports nurses and physicians in this identification.

Objectives: The aim of this project was (i) to deploy the implementation of ID-PALL in a neurology service of a university hospital in Switzerland, (ii) to assess the prevalence of patients in need of palliative care, and (iii) to evaluate the feasibility and acceptability of ID-PALL.

Methods: This implementation study was conducted between November 2022 and October 2023. First, a research nurse of the Palliative care service and a working group of the Neurology and neurosurgery service composed of nurses and physicians developed an implementation procedure for the use of ID-PALL ((i) training of nurses and physicians, (ii) weekly presence of the research nurse at the interprofessional decision-making colloquium, (iii) strategy for using the recommendations for good practice, (iv) creation of a pocket card to facilitate the daily use of ID-PALL, (v) adaptation of the electronic patient record). At the end of the implementation phase nurses and physicians answered a questionnaire and participated in focus groups to assess feasibility and acceptability.

Results: Eight trainings were given and 70% of the professionals were trained. ID-PALL was completed for 633 patients (40.5% of all patients), 36.3% of patients assessed needed general palliative care and 15.9%, specialised palliative care. 87% of participants were satisfied with the use of ID-PALL (satisfaction rating $\geqslant 8/10$), 90% reported that ID-PALL was easy to implement ($\geqslant 8/10$) and 87% reported clinical usefulness for their practice ($\geqslant 8/10$). Focus groups showed that ID-PALL promotes discussion within the medical and nursing team, validates a subjective clinical impression, and legitimises nursing requests to physicians. However, ID-PALL was rarely used by physicians and recommendations for good clinical practice were under utilised.

Conclusion: Training, day-to-day presence in the clinical field, and participation at the interprofessional colloquium are key determinants for successful implementation. The availability of hospital mobile consultation palliative care teams and the involvement of physicians remain crucial aspects to ensuring the continued use of ID-PALL.

ID: 302
Abstract Type: Poster

Topics: Relationships and connection, Educational approaches

Keywords: Emotion skills training, Medical education; Self-directed emotions, Scoping review protocol, medical students, Medical Curriculum

Methods of teaching medical students about the management and impact of their emotions in future patient care: A scoping review of the literature

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Background: Emotions of all involved in the clinical encounter are at the core of the clinical care process. However, a gap remains in teaching medical students how to recognise and deal with their own emotions.

Objectives: This systematic scoping review aims to identify what approaches have been implemented in medical education programs to teach medical students the skills to identify and manage the emotions they may experience in the physician-patient relationship and in the clinical environment.

Design: This scoping review follows the updated JBI methodology guidance for the conduct and reporting of systematic scoping reviews, and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).

Methods: We developed a search strategy combining terms related to the population (medical students, trainees, or residents), exposure (medical education, teaching methods, (undergraduate) curriculum) and outcomes (emotion regulation, psychological wellbeing, mental health) and applied the terms to five databases. Initially, 6726 references were included for abstract and title screening, of which 716 full-texts were reviewed. Data from the final included studies ($n>140$) is being extracted for analyses. The extraction tool includes a combination of items from the TIDieR and the PAGER frameworks, along with additional variables added by the authors.

Results: Based on the data extracted so far, studies have employed a variety of designs including qualitative, quantitative, and mixed-methods, using diverse teaching methods including lectures, reflective rounds, or reflective writing. Delivery formats comprise different modalities, teaching various aspects of emotions and emotion skills such as the meaning of death for students, guilt, or shame. The studies have targeted medical students all the way from year 1 to clinical years, as well as samples mixing medical students from different years. Other studies have mixed medical students with junior doctors or with students from other professions (e.g. social work, nursing).

Conclusion: The results of this scoping review will provide a novel overview of teaching methods employed to prepare medical students to identify and manage their own emotions in the clinical environment. The results will also support the development and implementation of training programs.

Funding: This review is being funded by the Swiss National Science Foundation (SNSF).

ID: 304
Abstract Type: Poster

Topics: Technology and digital innovations

Keywords: Advance care planning, electronic palliative care coordination system, end-of-life, palliative care, place of death.

PREPARE: Evaluation of Electronic Palliative Care Coordination Systems to support advance care planning for people living with life-threatening conditions: A retrospective observational cohort study

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Background: End-of-life care in the UK often takes place in hospitals, contrary to many people's preference for home care. Hospital care at the end of life is associated with invasive, costly and sometimes futile interventions. Electronic Palliative Care Coordination Systems (EPaCCS) have been introduced to support advance care planning (ACP) and to digitally document and share patients' end-of-life preferences across health services. Despite their widespread implementation their effectiveness and reach remain unclear.

Objectives: 1) examine EPaCCS utilization patterns; 2) examine the association between social determinants of health and EPaCCS creation and end of life care decision making; 3) compare EPaCCS outcomes and utilisation of health services for individuals with and without EPaCCS records.

Design: A retrospective observational cohort study will be conducted to analyse EPaCCS data from three regions in the UK. EPaCCs data will be linked with longitudinal primary/secondary and community care data in a quasi-experimental analysis to examine end of life care outcomes of those with and without EPaCCS records.

Methods: The data fields within EPaCCS systems will be described, examining their creation and content across three regions (London, Bradford, and Leeds). Social determinants of health (age, gender, ethnicity, and socioeconomic status) will be explored for their association with EPaCCS creation and the completion of ACP elements. Location of death and hospital utilization in the last 90 days of life as well as healthcare utilization costs for patients with and without EPaCCS records will be quantified.

Results: The findings will provide novel public health insights into the characteristics of individuals with an EPaCCS record, their impact on end-of-life decision-making and health service use. The study will present a comprehensive analysis of healthcare outcomes and costs associated with EPaCCS use, offering valuable information and insights for policymakers, health professionals and the public.

Conclusion: Whilst widely endorsed by the NHS, little evidence exists of EPaCCS benefits to patients, their families and society. This study will provide patients, clinicians, policymakers and health commissioners with valuable information into their continued use, where potential changes should be considered to enhance their delivery and implementation, and to what extent issues of inequity exist together with recommendations to 'level up' care.

ID: 305
Abstract Type: Oral presentation

Topics: Networks and compassionate communities, Educational approaches

Keywords: public education; capacity-building; health promotion

PalliLEARN: An international collaboration to bring palliative care education to everyone

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Background: A premise of the Compassionate Communities movement is that everyone has a role to play in supporting the people around them who are seriously ill, dying, caregiving and grieving. Yet many lack the confidence and knowledge to do so. Equipping community members to play an active role during sickness, dying and grief can better support those going through these experiences and reduce the burden on primary caregivers.

Objective: Build community capacity to partner in providing palliative care by developing, adapting and spreading an innovative public education program through local and international collaborations.

Design: Program development and delivery.

Methods: To address a health promotion gap within existing palliative care public education, a series of eight introductory one-hour courses was developed in Australia and delivered by organizational staff to public audiences. A partnership was subsequently formed with an Alberta-based organization that adapted four courses for use in Alberta, Canada. The Alberta adaptation of PalliLEARN relied on advice from a working group of palliative care clinicians and members of community organizations. A train-the-trainer model has subsequently been used to scale and spread the PalliLEARN program in both Australia and Alberta. Facilitators are required to be health professionals with palliative care experience, and to deliver the courses at low or no cost in their communities.

Results: The PalliLEARN public education program has expanded from being offered in one location to being delivered by teams of trained facilitators across Australia and in one Canadian province. Online and onsite courses are being hosted for the public by a range of community organizations, including hospice and palliative care societies, carer organizations, libraries and seniors-serving organizations. Participant evaluations indicate high satisfaction with the course content and facilitation.

Conclusion: Equipping and empowering the public to better understand and partner in providing palliative care is a key component of a public health educational approach and is being accomplished by building bridges at local and international levels. This collaboration provides a promising template for other organizations with similar aims.

Funding: Funding provided by the Australian palliative care peak jurisdictional organisations, Palliative Care Australia and the Government of Alberta.

ID: 306
Abstract Type: Oral presentation

Topics: The value of death, Networks and compassionate communities

Keywords: Caring Community, Hospiz, Philosophy, Research

Towards a "Caring Hospice"

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Idea: For the past 20 years, there has been an inpatient hospice in Eningen. With the necessity for a new building looming, the question arises: what might a future hospice look like and need? It should possess the flexibility to cater to the diverse needs of individuals and their families. Temporary stays in the hospice should offer experiences of community, counselling, and respite. If a hospice adopts a perspective of being part of a caring community, it can foster a societal attitude of compassion across all areas of life. The Eningen Hospice, in collaboration with various individuals and organizations in the region, feels a responsibility for fostering and encouraging the coexistence among people of all ages and circumstances, be they healthy, ill, or at the end of life. A hospice should be a place where individuals can find purpose, engage in dialogue, seek guidance in various life situations, take part in cultural activities, and like in many other parts of our society, experience the end of life. This prompts the question: what are the specific needs of a caring community in relation to a hospice?

Implementation: Through workshops involving volunteers and full-time staff, the initial step was to gather insights into what aspects should be preserved, reconsidered, or innovated in a new hospice. Concurrently, a project was initiated as part of a caring community initiative, aiming to provide philosophical inspiration for the community and, consequently, for the hospice's development process. A workshop is scheduled for June 2024, where residents of Eningen will be empowered to identify and discuss fundamental topics and philosophical questions directly related to their daily lives. Facilitated by philosophical practitioners, they will devise mini-interventions within their surroundings, offering philosophical inspiration for the Caring Community of Eningen and the hospice project. Philosophy can be experienced as a shared space for resonance. In Autumn 2024, there will be an evaluation of the process and outcomes, which will subsequently be integrated into the hospice project.

Conclusions: Thesis: For the nurturing of a compassionate society, including a compassionate hospice within this society, there must be room for fundamental contemplation and reflection. Philosophy intertwined with everyday life can provide such space and yield valuable insights for future requirements and advancements.

ID: 307
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving

Keywords: Cultural identities, Minority Ethnic Group, Palliative care research, End-of-life experiences, Ethnic identity

Cultural identities in palliative care research: A critical reflection on defining and categorising minority ethnic groups in end-of-Life care

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Background: Palliative care research is often challenged by a lack of standardised definition and classification of minority ethnic groups. This study encourages a critical examination of the meaningfulness and significance of these classifications in the context of cultural identities and the complexity of the term "minority ethnic group" and implications of its application in research.

Objective: To reflect on the multifaceted dimensions of ethnicity within the palliative care research framework, particularly how individuals self-identify and navigate cultural complexities within the context of life-limiting illnesses including their experiences related to death and dying.

Design: Qualitative study with interviews and observations.

Methods: We recruited 6 patients from minority ethnic groups out of our target sample of 20 from two sites delivering care for people with life-limiting conditions in London.

Results: Preliminary findings revealed challenges in categorising individuals within minority groups, emphasising the complex nature of cultural identities including views on death and end-of-life experiences. As standardised classifications were used, these categories may oversimply and homogenise diverse experiences, potentially overlooking the richness and variability within minority ethnic population. This could become a challenge when exploring dimensions of cultural, religious and spiritual experiences in palliative care particularly concerning perspectives related to death and dying, where self-identification may allow a more comprehensive representation.

Conclusion: This study suggests the need for an approach attuned to cultural considerations in palliative care research and recognises the challenges in recruitment associated with using official government definition and categories. It aims to encourage a reflective examination of the inherent assumptions and limitations associated with employing standardised categories, thereby, encouraging a revaluation of existing frameworks and the potential development of more contextually relevant categories. An absence of distinct boundaries between culture, ethnicity and nationality may hinder the development of effective policies. Recognising the limitations and fluidity of ethnic identity may foster a comprehensive understanding of the palliative care experiences and perspectives on death and dying within ethnic minority communities.

ID: 308

Abstract Type: Poster

Topics: Relationships and connection, Educational approaches

Keywords: Indigenous communities, palliative care education, community-based, cultural safety, equity

Developing accessible and culturally relevant palliative care education for Indigenous communities in Canada

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Background: Community-based research conducted in Canada in partnership with Indigenous communities revealed that education for healthcare providers, family members, and community members is crucial for the development of sustainable palliative care services in Indigenous communities. However, there is a lack of culturally relevant education that reflects the physical, cultural, and social care needs of Indigenous communities. To address this gap in knowledge, our Centre partnered with Indigenous communities across Canada to develop educational resources to meet the needs of Indigenous peoples.

Objectives: This poster outlines an educational initiative that aims to enhance the capacity of Indigenous communities to provide palliative care through culturally safer palliative care training for family and community caregivers. This initiative is designed as one step in the larger process of developing comprehensive palliative care services for Indigenous peoples.

Design: The curriculum design process is centred around building authentic, respectful, and collaborative partnerships with Indigenous communities. We prioritize an Indigenous-led and driven approach that recognizes and honours Indigenous Knowledge, worldviews, and guiding principles. The curricula combine wholistic teaching concepts that focus on Indigenous health and balance with the palliative approach to care.

Results: This poster presents a suite of newly created resources developed in partnership with Elders, Knowledge Carriers and Indigenous organizations, scholars and health and social care providers. Four culturally relevant curricula will be presented which have been designed for all levels of community care, including training for registered and unregistered health and social care providers, as well as family and community caregivers. The curricula are grounded in the Indigenous Wellness Framework, which incorporates community's experiences, culture, values, and beliefs into the education.

Conclusion: Through community-based initiatives, Indigenous communities are developing caregiving models and practices based on individual, family, and community worldviews. This poster presents the process undertaken by our education team to develop culturally safe-r palliative care training for health and social care providers serving Indigenous communities. The training increases Indigenous communities' capacity to provide palliative care.

ID: 309

Abstract Type: Oral presentation

Topics: Networks and compassionate communities, Educational approaches

Keywords: continuing professional education, advance care planning, medical legal partnerships, health justice partnerships, health promotion

Continuing legal education on advance care planning: multi-sectoral partners co-develop a curriculum to increase clinical understanding, equip champions and evaluate best practices

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Background: To maximize the potential of advance care planning (ACP) to improve quality of care, scholars and practitioners advocate for interdisciplinary collaboration including medical legal partnerships (MLPs). We implement our framework for health-legal collaboration, which aims to overcome professional silos, align legal practice to clinical reality and improve support for individuals.

Objective: To develop a CLE curriculum to: cultivate understanding of practice contexts and cultures; identify gaps in policy and practice;

jointly develop and disseminate best practices; and recruit volunteers for public education.

Design: Program development and delivery.

Methods: Data and feedback from a survey of lawyers, joint education, engagement events (n=13), stakeholder interviews, and literature provided understanding on: local delivery of CLE; learning preferences; barriers, knowledge gaps and needs; complaints to public guardian; MLPs; and similar curricula. A curriculum of ACP elements, case studies, context from legal, health and government sectors, and best practices was developed and found acceptable by experts. The local non-profit CLE provider ("the Provider") agreed to host a course (faculty: palliative care physician, wills and estates lawyer, clinical ethicist and Office of the Public Guardian and Trustee subject matter expert). The recording and materials will be accessible to the bar and students (n=10,500) through the Provider's library.

Results: As the primary source of CLE programs and resources in the jurisdiction, the Provider leads evaluation of suitable courses for the profession; their agreement to host recognizes it is *prima facie* acceptable. Results from a pilot test with the bar association (elder law group) were positive. The course was well subscribed (n=13), attendees asked substantive questions, and responded to polls on resources' usefulness. The chairperson of the group rated the course as very satisfactory, and said it increased their interest in raising awareness of ACP and volunteering on project activities.

Conclusion: The course will be offered to the legal profession in April 2024 and evaluated by attendees. The curriculum is being submitted for inclusion in law schools' wills and estates and health law courses, and as the foundation for joint education with health and financial sectors.

Funding was provided by the Government of Alberta. Opinions expressed do not necessarily reflect the Alberta government's policy or position.

ID: 310
Abstract Type: Oral presentation

Topics: Death and grief literacy, Artistic and creative approaches

Keywords: dying, death, death literacy, arts-based approaches, young adults, narrative

Using narrative data to engage young adults in conversations about dying and death

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Background: Denial and cultural silence around dying and death are significant social issues of our time, and the impact on young adults has been greater than for other groups. 'Death literacy' has emerged as a field within a larger education movement to support individuals, health and social professionals and the public more broadly through awareness, understanding and dialogue. Death literacy encompasses cultivating the knowledge and skills to access, understand, and act upon end-of-life and death care options. Creative strategies, such as arts-based approaches, may be particularly relevant to the needs of young adults, yet research has been limited to date.

Objectives: The aim of this knowledge translation project was to translate existing illness and palliative care narrative data using arts-based approaches into animation and other arts forms as a way to emotionally engage with young adults on this topic and consider creative products within future educational initiatives.

Design and Methods: We co-designed a pilot course for undergraduate art and design students, involving researchers, students and faculty, to explore arts-based approaches to understanding narrative, palliative care qualitative data. The data came from Smith's narrative ethnographic PhD research – an investigation of the experiences of families waiting for a transplant for their child or receiving palliative care, as well as the experiences of their healthcare providers. Selected, anonymized text (focused on empathy, illness, suffering, and death-related themes) from 145 journal entries of 18 healthcare providers was used in the pilot course. Four students enrolled and worked with this material to create different arts-based forms (e.g., collages/moodboards, sketches, digital drawings, sequential narratives/storyboards, journey mapping). Students were guided to select moments, emotions, and feeling states to reflect in their artwork.

Results: Apart from the arts-based products, we learned that the young adult students were open to talking about concepts of dying and death and wanted to engage further in this type of knowledge creation around sensitive health topics. On this basis, we developed a proposal for deeper exploration of art-based approaches to enhance death literacy in young adults.

Conclusion: We contribute creative ways of compassionately and emotionally engaging young adults to support communication about dying and death and other sensitive health topics.

ID: 311
Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: Compassionate Cities Charter Civic

Compassionate Bunbury Charter and Toolkit – Fostering community conversations and civic actions

Julieanne Hilbers, Samar Aoun
Perron Institute

Background: Given their role in community engagement and wellbeing, local government is well positioned to be an active player in supporting Compassionate Communities. This presentation focuses on the development of the Compassionate Bunbury Charter and Toolkit which built on previous work undertaken with this City of Bunbury (in Western Australia) over a number of years. The Compassionate Bunbury Charter is a whole of community responsibility; it contains aspirations that relate to community members, service providers, businesses, organisations, groups and clubs to pursue. It provides a pathway for Bunbury becoming a Compassionate City.

Objectives: Explore how Compassionate City Charters and Toolkits can foster community conversations and civic actions.

Design: Discuss how the Compassionate Bunbury Charter and Toolkit was developed, how it actions the principles of the Ottawa Charter and describe challenges experienced along the way.

Methods: The Charter was informed by community consultations with City of Bunbury Councillors and employees, chaplains, monks, new migrants, carers, retirees, people with life-limiting illnesses and Aboriginal members of the community. We also sought input from the wider community online via the City of Bunbury Community engagement hub and social media. Interviews with subsequently undertaken with community leaders and presentations made at community forums.

Results: The Compassionate Bunbury Charter recognises the role we all can play in fostering community conversations and actions around caring, dying and grieving. Ten themes were identified during community consultations. The Charter is accompanied by a Toolkit which outlines practical actions people can undertake individually and collectively. The Charter has led to a number of people and organisations pledging to take action. Examples of pledges and actions will be shared including the development of the Compassionate Bunbury Mayor award.

ID: 312
Abstract Type: Workshop

Topics: Research methods, Networks and compassionate communities

Keywords: Compassionate Communities Evaluation Social Economic

Evaluating Compassionate Communities initiatives: Learnings from the Compassionate Connector program

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Target Audience: Researchers, project managers, service providers and community workers interested in demonstrating the social and economic benefits of Compassionate Communities approaches to caring, dying and grieving.

Learning Objectives: Greater awareness of what practical evaluation tools can be used for demonstrating outcomes of Compassionate Communities programs and initiatives and how to navigate the health service and community aspects of the challenges.

Structure of Workshop: In Western Australia (WA), the South West Compassionate Communities Network in partnership with WA Country Health Service care teams implemented the Compassionate Communities Connectors program (2020-22). This translational research project involved Community volunteers (known as “Connectors”) being trained to enlist helpers from the community (known as Caring Helpers) to enhance supportive networks and provide practical and social support to people with advanced chronic conditions and/or life-limiting illnesses.

This workshop will share the range of quantitative and qualitative evaluation tools that were used to identify social and practical gains for participants (Connectors, families and healthcare providers), including health care usage method to identify the cost savings for health services.

The workshop will further explain the rationale and methodology used to identify the social and economic impact of this approach and explore how this methodology and tools can be used to support attendees' work. Interactive discussions will explore what evaluation tools attendees have used for the different target groups in their programs, what they were aiming to achieve and what worked or did not work when formal and informal networks have partnered together.

ID: 313

Abstract Type: Oral presentation

Topics: Death and grief literacy

Keywords: Death literacy, death literacy index, survey design

Death Literacy Index: the development of the short form DLI-9

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Background: The Death Literacy Index (DLI) was developed to address the need to demonstrate one aspect of community-based outcomes in the field of public health palliative care. The DLI was developed in 2019 in Australia, and validated versions have been published in the UK, China, Turkey and Sweden with learning and refinement of the survey tool. As such, this research presentation provides a revised DLI and the 9-item short form.

Objectives: This presentation reports on the development and psychometric properties of the DLI-Revised and a shorter version of the tool the DLI-9.

Design: Quantitative Research, survey development.

Methods: Online panel representative of 1202 Australian adults, based on age, gender, and location. The items on the scale were revised by a team of death literacy experts and a Confirmatory Factor Analysis (CFA) was conducted on the revised DLI using the model outlined in previous research. To develop a shorter version, 16 items were initially selected based on face validity. An Exploratory Factor Analysis (EFA) was run to reduce the number of items with factor loadings less than 0.65 and to identify the factor structure. The newly configured model was assessed for model fit using CFA. The invariance of the final model was tested across genders using multi-group CFA.

Scaled mean scores between the DLI-revised and the shorter version were assessed for statistical differences. The internal reliability of the DLI-revised and shorter version was assessed using Cronbach's alpha.

Results: Twenty questions were modified in the revised scale. A CFA on the 29-item revised DLI indicated a good model fit [TLI.93; CFI.93, RMSEA.06; SRMR 0.06], with 6 latent variables and an underlying latent variable "death literacy".

For the shorter version, an EFA identified a 9-item, two-factor structure model. The model demonstrated an excellent fit with TLI and CFI values exceeding 0.95 and SRMR less than 0.05. The measurement invariance showed a comparable means between males and females. The DLI-9 and DLI-29 were strongly correlated (0.98).

Cronbach's alpha coefficients for both revised DLI scales and subscales and the shorter version of the DLI exceeded 0.8, indicating high internal consistency.

Conclusion: The DLI-revised and the DLI-9 were found to have good psychometric properties. The development of a shorter version of the DLI, provides a valid shorter tool for community organisations. Recommendations for using the DLI-9 will be discussed in the presentation.

ID: 314

Abstract Type: Poster

Topics: Death and grief literacy

Keywords: Death Literacy, Death Literacy Index, COVID-19, Voluntary Assisted Dying

Death Literacy in Australia: Did COVID-19 and the introduction of Voluntary Assisted Dying have an impact?

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Background: Population studies indicate that people and communities develop death literacy through personal experience, arts and education programs. A nationally representative study of death literacy and death-related experiences was conducted in Australia in 2019 and 2023. Between 2019 and 2023 there were two significant social and medical events: the COVID-19 pandemic and the introduction of Voluntary Assisted Dying (VAD) laws. This study examines the impact of VAD and COVID-19 on death literacy.

Objectives: Using representative population data from Australia, this presentation examines the association between death literacy and personal experiences with both COVID-19 and the introduction of VAD in Australia.

Design: Quantitative research using a national representative sample.

Methods: The 72-item questionnaire was administered in an online format (via computer, iPad or mobile phone). A descriptive and regression analysis using SPSS 29.0 was carried out to examine the relationship of COVID-19 and VAD-related experiences with scaled mean scores on the death literacy index. Multivariate analysis is planned to control for potential confounding variables.

Results: A total of 1202 people completed the online survey. The 2023 population study revealed an increase in overall death literacy.

295 (24.5%) reported that they had learnt about end-of-life issues, including death, dying, and grief, because of the COVID-19 pandemic. One in twenty people (67) cared for someone dying with COVID-19, while one in ten (135) experienced the death of a close family member or friend due to COVID-19. Two in ten (219) knew someone who died from COVID-19. Around 28% (341) of the participants attended a funeral, while 10% (111) organised a funeral during the pandemic.

Similarly, 303 participants (25.2%) said that they learnt about end-of-life issues because of the introduction of VAD laws in Australia. Nearly 5% (59) reported having a caring role for someone approved for VAD. Ninety participants knew someone planning to use VAD, while 80 knew people who died using VAD.

Participants reporting any form of experience related to the COVID-19 pandemic and VAD had significantly higher death literacy scores (including scores on overall index, scales and subscales) than those who did not.

Conclusion: It has been previously reported that Death Literacy is a concept that develops through personal, work and education experiences. This study provides further insights into the development of death literacy.

ID: 315
Abstract Type: Poster

Topics: Relationships and connection, Networks and compassionate communities

Keywords: Bereavement, COVID-19, Death, Funeral Directors, Indigenous

Unsung heroes of COVID-19: Funeral directors' compassionate care of Indigenous families and communities

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University of Auckland, New Zealand

Background: New Zealand's COVID-19 Tangihanga (funeral) policies required a tūpāpaku (body) to be uplifted by a Funeral Director immediately after a Death Certificate was completed. Indigenous whānau (family including extended family), were unable to employ their tikanga (customs) during lockdown. Māori customs require the deceased's body to be with them at a marae (meeting house), or private home, several days before internment. What helped whānau during this challenging time?

Objectives: We aimed to explore bereaved Māori whānau experiences of providing end-of-life care to someone with a terminal illness, and conducting funerals during COVID-19 Lockdown. We wanted to explore the perspectives of whānau, health professionals and Funeral Directors to understand what helped or hindered whānau.

Design: We used qualitative Kaupapa Māori Research methods to investigate bereaved whānau experiences, health professionals' perspectives, and the role of Funeral Directors in supporting whānau. Findings were published as whānau pūrākau (stories) and portraits; these were disseminated via a virtual reality online exhibition using Arts Based Knowledge Translation methods and as a book.

Methods: We conducted twenty-nine face-to-face interviews with whānau in four regions. Community research collaborators supported recruitment. We interviewed 23 health professionals and community support people and seventeen Funeral Directors. A Kaupapa Māori-centred inductive thematic analysis was used to analyse and interpret the data.

Findings: Whānau were distressed; marae were closed and tūpāpaku were being uplifted and cremated. Funeral Directors took care of transfers and social distancing. They found 'grey areas' to adapt policies and cultural customs. To support bereavement, they drove slowly through rural communities; people could view the body and perform cultural rituals. Funeral Directors thought the pandemic funeral policies did not cater for bereaved whānau. Some whānau were impacted by the additional funeral expenses.

Conclusion: Compassionate, culturally aware Funeral Directors supported Indigenous whānau and communities. As death experts, they should be more involved in pandemic funeral planning. Government should consider remunerating additional funeral expenses during pandemics.

ID: 316
Abstract Type: Poster

Topics: Policy and advocacy

Keywords: children, palliative care, utilization, hospital

Palliative care services among hospitalized children with life-limiting conditions in the U.S.

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Background: Pediatric palliative care (PC) is primarily centered around enhancing the quality of life for children facing life-limiting illnesses and their families. Some common illnesses utilizing pediatric PC include congenital anomalies, neurodegenerative disorders, genetic syndromes, and cancer. Pediatric PC research identifies gaps in current care approaches, promotes evidence-based interventions, and encourages the integration of PC into standard pediatric healthcare. There is a body of knowledge regarding PC among adults, but it is scarce when coming to pediatric PC.

Objectives: To examine trends of PC among children with life-limiting clinical, as well as sociodemographic and clinical factors associated with PC.

Design: The 2016-2020 national inpatient sample (NIS) were used in this pooled cross-sectional study.

Approach: A total of 684,746 hospital discharges under 18 years old with life-limiting conditions were analyzed. Use of PC, mortality, and LOS, as well as associated sociodemographic factors were examined.

Results/Findings: Neurologic/neuromuscular, cardiovascular, and premature/neonatal conditions were ranked in the top three of all pediatric conditions that may need PC. Use of PC increased from 1.47% in 2016 to 1.80% in 2020, with an average 7.8% annual increase in the odds of receiving PC. Females (odds ratio (OR)=1.06 as compared to males), uninsured (OR=1.73 as compared to patients with private insurance), and patients living in low-income areas were more likely to receive PC. Children with a higher level of severity of illness (OR=2.54 per level of increase), including neurologic/neuromuscular (OR=2.63), and malignancy (OR=3.29), tended to receive PC. Children residing in rural areas were less likely to receive PC (OR=0.51 as opposed to patients living in non-rural areas). Children receiving PC were much more likely to die in hospital (OR=23.16) and to incur a longer hospital stay than their counterparts without PC.

Conclusions and Application to PHPC: Pediatric inpatient care increased from 2016 to 2020. Hospital PC was associated with severe clinical conditions, uninsured, rural residence, in-hospital death and LOS. Better health insurance compensation on PC and earlier referral to PC for hospitalized children with life-limiting conditions may improve their quality of life and disease management.

ID: 318

Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, Death and grief literacy

Keywords: Mortality Risk, Older People, MMRI-R, Home Care

Implementation and Validation of a Mortality Risk Assessment Tool to Enable End-of-Life Care at Home for Older People in Western Australia

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Background: Most older Australians state they prefer to die at home, yet less than 15% experience a home death. Timely recognition of the likelihood of death is important for planning End-of-life (EOL) care at home. The Minimum dataset Mortality Risk Index – Revised (MMRI-R) was initially developed to predict 6-month mortality for older adults in residential aged care and was later validated in other clinical settings. The MMRI-R is yet to be used in the Australian Home Care Context.

Objective: This study aims to evaluate the feasibility of translating an existing published evidence-based method of mortality risk assessment using MMRI-R to the care of older people receiving aged care at home in Western Australia.

Design: Retrospective cohort study design.

Methods: The study will be conducted using the retrospective data gathered from over 2000 client health assessment records of a large Home Care Provider (HCP) in Western Australia. As a part of their care planning process, this HCP introduced the MMRI-R as an evidence-based mortality risk assessment tool, for older adults receiving aged care at home. The criteria for the tool are integrated into the electronic assessment system as a part of their practice focus, on improving end-of-life care. Assessment using the MMRI-R does not require any additional physical assessment of the clients. The MMRI-R score is calculated automatically once the home care staff fills out the routine assessment forms.

Results: Anonymous risk index scores at 1 and 3 months and mortality outcomes at 6 months will be generated. The feasibility of integrating MMRI-R into the standard care system of home care provision will be assessed. MMRI-R scores will be mapped against outcome measures including deaths and other hospitalizations.

Conclusion: This project informs a larger body of work focused on implementing a practice change to enable dying at home through developing an effective person and family-centered community care planning model. Identifying the risk of death will assist home care teams, families, and informal carers to enable individual preferences for EOL care at home.

ID: 319

Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving

Keywords: caregiving, end of life, death, dying, culture

Caring for the Sick and Dying in the Philippines: Is it Traditional and Modern Today?

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Background: In history, Philippines had been one of the most attractive colonies in the world with 3 different colonizers i.e. Spain, USA, and Japan with the longest colonization of 333 years by Spain. This had a great impact on the formation of customs and traditions around the care of the sick and dying among Filipinos that are influenced by religion and traditional belief systems. It is noteworthy that during the pre-colonial Philippines, there were established tribes and ethnicities like the Tagalog, Igorot, Badjao, etc. that have strong and rich culture and traditions and are still evident today. This paper highlights the blending of Filipino culture and religion around caring for the sick and the dying.

Objectives: To describe the Filipino traditions surrounding the care of people who are sick and at the end of life

Design: This paper was based on textual references such as published journal articles, editorials, official websites of private and government agencies; a personal testimony, and interviews with focused group discussions.

Method: A thematic analysis was made based on the following questions:

- Most communities/regions in the world have their own traditions, customs, and history of caring for the sick and people at the end of life.
    - → Describe the systems/traditions which were or still are in place in your region.
    - → Discuss the similarities and differences with concepts in modern palliative care.
    - → Is there a scope for integration?

Results: Similarities and differences of practices in Filipino culture and Modern Palliative Care were described based on the following themes: *Preferences of care, Communication patterns, Decision-making process, Healing methods, and Other psychosocial support*. Generally, there is a stigma on discussing death in the Filipino culture. Filipinos prefer to be cared for at home and opt for less aggressive management at the end of life. Decision-making is family-centered and is highly influenced by who supports the patient financially as a sign of gratitude and respect. People living in less civilized areas prefer traditional healing methods as initial care while people living in more civilized areas prefer modern medicine. Lastly, *Bayanihan* is a concept of volunteerism among Filipinos where members of the family or community willingly contribute to care for the sick and the dying person.

Conclusion: The care of the sick and the dying in Filipino culture is highly influenced by its history, religion, and the evolving modernization.

ID: 320

Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: Compassionate Communities, process evaluaton

Facilitators and barriers to developing Compassionate Neighbourhoods

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Background: In 2020, we developed two Compassionate Neighbourhoods in Sint-Kruis and Herzele to promote neighbourhood participation in matters of serious illness, death, and loss. Existing literature describes reasons for initiating such initiatives and highlights ongoing activities but falls short in exploring contextual barriers and facilitators to their development.

Aim: To explore the contextual factors that facilitate or hinder the development of a Compassionate Neighbourhood in Sint-Kruis

Design: Between January 2020 and September 2023, we implemented and evaluated two compassionate neighbourhoods, of which Sint-Kruis was one. We conducted a qualitative process evaluation.

Methods: The process evaluation consisted of observing meetings and actions (n=102) and conducting interviews and group discussions (n=57) with stakeholders, including social partners, local merchants and the neighbourhood police. We conducted a reflexive thematic analysis, employing a mix of inductive and deductive coding based on the Consolidated Framework for Implementation Research.

Results: We identified the city as the project initiator as a key contextual factor. This facilitated the project by anchoring it in a structure consisting of a steering group of social partners, and by appointing a project leader and a neighbourhood worker who were mandated to coordinate the project. However, while this structural anchoring was beneficial, it also hindered the project. Social partners expressed concerns that excessive time was devoted to developing these structures rather than implementing actions in the neighbourhood. The decision to appoint an external neighbourhood worker hindered the sense of ownership among social partners since some of them already had neighbourhood workers present in the area. Redistributing the responsibilities of the neighbourhood worker to the social partners, facilitated a greater sense of responsibility towards the project and motivation to continue. Pre-existing collaborations between the city and social partners facilitated bringing partners together but impeded the involvement of more unconventional social partners (e.g. neighbourhood police and local merchants).

Conclusion: The city's role in initiating the project laid a strong foundation through structured leadership and organisation. Finding a balance between structure and empowerment of the participants is found pivotal to creating sustainable Compassionate Community initiatives.

ID: 321

Abstract Type: Poster

Topics: Educational approaches

Keywords: Spiritual care; Education

Advanced training program in Spiritual Care Competence: insights from Spirituality Ibero-American Forum

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Background: Palliative care (PC) professionals should be aware of spirituality as a human being's essence. We must overcome the biopsychosocial paradigm to a more fully lived experience approach in spiritual care (SC). Advanced training in SC is common in Anglo-Saxon countries, but in the Spanish-speaking, the initiatives have been few and out of the higher education settings.

Aim: To develop an innovative SC education program based on five SC competencies of the European Association for Palliative Care (EAPC).

Design: This Ibero-American advanced educational program was conceptualized in two phases: 1) operationalization of the EAPC competencies in indicators made by a transnational team of experts composed of pedagogues, physicians, psychologists, and nurses with large experience in PC; and 2) design of specific content and activities for those SC competencies development-based on Kolb cycle of experiential learning, "Harvard Project Zero" learning methodology and narrative pedagogy using "Action Learning System".

Results: We have structured an online course with weekly synchronous sessions and scheduled asynchronous student work. It is structured into 45 sessions (lasting 120 minutes, each). All the content has been structured in six subjects: 1) core concepts in spirituality and SC; 2) self-awareness and spirituality; 3) basis of spiritual accompaniment; 4) spiritual accompaniment in the clinical practice; spiritual care in special conditions and vulnerable groups; and 6) knowledge translation into practice. The synchronous part consists of 3 types of sessions: "general sessions" (meet the experts and lectures); "nuclear sessions": tutorial small groups work; "integration sessions": reflective practice to foster decision making and critical thinking. Asynchronous sessions include discussion forums, self-made narratives, suggested readings, and reflective writings. For course evaluation, we use a mixed-method approach: written assignments, e-portfolios, reflective diaries, and a final project on SC in practice.

Conclusion: This course is ongoing on the 3rd edition with a high demand of participants from several geographical areas and backgrounds. The expected learning outcomes include intra-, inter-, and transpersonal development in suffering attendance and deepening compassion in professional settings. Further research should address the different expertise levels of spiritual care competence.

ID: 322

Abstract Type: Poster

Topics: Relationships and connection, Care in humanitarian contexts

Keywords: advanced cancer, patients, relatives, peer support, quality of life, video conferencing

How is peer support expressed within the "Living with Cancer" programme?

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Background: In advanced cancer support from peers, who have experiential knowledge of and experience with the consequences of living with cancer, may increase resilience and improve quality of life. Peer support includes informational, emotional and appraisal support. The “Living with Cancer” programme is a peer-led peer support programme for persons living with advanced cancer and relatives of those persons. Participants join six weekly video-conferencing group meetings of 1,5 hours per session, guided by a trained peer-facilitator.

Objectives: The aim of this study is to find out how peer support is expressed in the ‘‘Living with Cancer’’ programme.

Design: In this observational study the video recordings of the meetings were used to retrospectively observe and analyse the behaviour and interaction between participants and facilitators.

Methods: A total of 26 meetings were analysed, from 11 different groups. We used a literature based framework, clarifying existing types of peer support to develop a coding scheme for data extraction. Deductive analysis was performed and codes and quotes were arranged thematically.

Results: Peer support occurred in different types of interaction: from participant to participant (patient- relative; patient - patient and relative-relative) and from facilitator to participant (both script based and peer based). Most frequent observed peer support was informational support, such as sharing relevant knowledge and sharing alternative courses of action. Appraisal support was expressed in encouragement to persist in problem resolution and positive reinforcement upon achievement. Emotional support was reflected in expressions such as : ‘caring’, ‘provide reassurance’, ‘being empathetic’ and ‘being respectful’.

Conclusion: This study shows that the online ‘‘Living with Cancer’’ programme, in which persons living with advanced cancer and their relatives participate in video-conferencing group meetings, enables participants and facilitators to share their experiential knowledge and support others in various ways.

ID: 323
Abstract Type: Oral presentation

Topics: Relationships and connection, Networks and compassionate communities

Keywords: compassionate schools

Normalizing death, grief, loss and care in a University of Applied Sciences community

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Background: Students and staff at Rotterdam University of Applied Sciences (RUAS) experience death, grief, loss, and care (DGLC). This often affects their work and study. The population of RUAS comprises 40,000 students and 4,000 staff members, a community in itself.

Objectives: Awareness, attention and compassion for experiences with DGLC within the RUAS community.

Design: An action research approach in which working towards change as well as developing knowledge is used on the way to a Compassionate University of Applied Sciences (C-UAS).

Methods: From 2021 on, actions were planned to address issues related to DGLC, focussing on students and employees. Monthly “drops” (small interventions) were performed, evaluated and continued or followed-up by new actions. We also held several interdisciplinary meetings to exchange on experiences concerning DGLC.

Results: The concept for the C-UAS was very well received by the Board of Directors.

Online dialogue sessions involving discussions with both students and staff were held, revealing that many students grapple with grief and loss. Interviews were conducted among staff regarding their experiences with DGLC in the workplace, highlighting an individualised need for attention at these subjects.

In a minor course on palliative care, students undertook an assignment on art and grief, interviewing fellow students on the subject. This resulted into a recommendation for the incorporation of art-based solace in RUAS.

Furthermore, various “drops” were implemented to draw attention to DGLC. These included the director’s acknowledgment of grief and loss at the academic year opening; a table in the central hall featuring a journal for anyone to write about what matters, along with cards containing inspiring questions that passersby can answer; and posters focusing on DGLC. In “living room conversations” staff and students shared stories about DGLC; evaluation indicated that sharing personal experiences in a safe space at school and workplace, fulfilled a need to feel heard and understood, a practice they wish to continue.

We contributed to the film 'Connecting Communities – Inspiring perspectives on palliative care' by Agora and PZNL, launched during the 2023 EAPC World Congress. Amongst other initiatives, the film portrays the development of the C-UAS.

Conclusion: Our actions contribute to normalizing experiences, reducing taboos, and raising awareness about DGLC in the daily lives of students and staff in our RUAS community.

ID: 324

Abstract Type: Oral presentation

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: Hospice culture, young adults, volunteering, participation

Young people discovering death, dying and grief – How dialogue culture could pave the way for voluntary work in hospice care

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Idea: Two observations in hospice services and grief counselling of Malteser Germany resulted in this project. 1) Severely ill young clients wished for volunteers the same age as they are, which are currently rare. 2) Teens and young adults hospice volunteers met during projects on death literacy at school wished to get more involved in hospice movement themselves. But hospice services lack experience with volunteers under the age of 30. Main goals are to experiment on new ways to bring young adults in contact with hospice care, grief counselling and related topics, to broaden the possibilities of voluntary work in hospice movement and to develop various training formats to prepare people for volunteering. Therefore, ways of working and structures of services and institutions need to be evaluated and adjusted.

Implementation: During 2019 to 2022 twelve chosen hospice services and facilities in Germany implemented individual ideas how to get in contact and work with young adults within their local structures. During three annual collective meetings moderated by researchers (KW, PS) project ideas and results were discussed and counselled, best practices shared and new inspiration for local projects given. Finally, findings and ideas were share with the hospice movement in a symposium and a workbook. All over the project active participation of young people is a central feature.

Lessons learned: Most important, young adults wish to take responsibility for a caring society. Therefore, create opportunities for young adults to start a dialogue about life and death and to get to know the hospice movement and its central qualities. Cooperations with different educational and cultural institutions are recommended.

When interested, offer gradually intensifying ways of engaging in hospice movement to enable a prompt start in volunteering and first practical experiences for young adults they can further build on.

Within services and institutions value diversity in people, tasks and ways of training and supervision. Thus, acknowledge individual strengths and experiences different people contribute to the movement. Bring together the new and young and the old and approved as both share the same core values of hospice care and their motivation for volunteering is similar.

Finally, volunteers in hospice movement are more than companions to the dying. They serve as multiplier of the hospice culture within their own peer groups contributing to increasing death literacy in society.

ID: 326

Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: Compassionate, Community, Palliative Care, Kalasin

The model development of compassionate community in Thailand from the study of Kalasin municipality's community-based palliative care service for the end of life elderly patients and their families

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Background: Thai community culture supports the palliative care service, particularly the Northeastern, strong kinship, respect and grateful for the senior, caring for their well-being. The senior's health care is supported by family and community, found many Thai blessing ceremonies. Kalasin's palliative care service(PCS) is a successful case, mutual collaboration for health reliability, relevant to the compassionate communities(CC).

Objectives: To comparative study PCS for the elderly and their families of Kalasin Municipality (KM)'s CC,with Kerala's care model. To develop Thailand's the upper Northeastern's CC model. To recommend CC development model guideline.

Methods: Review on public health approach to palliative care, CC, Kerala's palliative care model and Thailand's PCS policy. Survey and study KM's PCS upon 9 CC characteristics; 1 local health policies 2 the vulnerable's needs 3 diversity 4PCS action policy 5 various communications 6reconciliation and loss promotion 7 easy assessment 8 inclusive plan 9 spiritual care, and 5 functions of CC charter(CCC); 1 awareness 2 innovations and collectiveness 3 action plan 4 new alliances 5 social change, during 2020-2022. In-depth interview 30 key informants, 2 focus group meetings and 3 site visits; KM's managements and operations, Muang Nam Dum volunteer group, local networks and experts. Synthesis CC model and conclude guideline recommendations.

Results: KM Volunteer Network (KVN), starting 2018, aligned with 9 characteristics and 5 functions, evident from KM's Constitution for Healthy (2016), Healthy City policy and annual budget. KVN(KM, health care workers (HCWs) and community) as social service with care and support, funded by community's resources,communicating via social media,raising awareness of mutual trust,collaboration and reciprocity. Kalasin Compassionate Community Learning Center (KCCLC), the found CC model, managed by steering committee of 3 parties(KM, HCWs and community), controlling safety and quality standard. KCCLC role was as center of knowledge, resource supporting and CC promoting, funded by public and private. The recommendations for transparency and SMART principle governance,cultural-based curriculums and its ecosystem.

Conclusion: KVN aligned with 9 CC characteristics and 5 CCC functions,enhancing community engagement and awareness about relationship of death and living,relied on mutual trust,collaboration and reciprocity. KCCLC and its governance model should be expanded to Thai upper Northeastern administrations.

ID: 327

Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Policy and advocacy

Keywords: preferences, palliative care; place of death, public health, trends

Major discrepancy between peoples' preferences for place of care and dying and actual place of death in Sweden

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Background and study aim: Swedish palliative care policy, launched in 2012, emphasize peoples' right to participate in the planning and decision-making about their end-of-life care, including where to receive the care and die. This abstract presents two studies with the interest in disclosing potential policy responses by investigating Swedish peoples' preferences for place of end-of-life care and dying, and longitudinal trends in place of death within the adult Swedish population from 2013 to 2019.

Methods: The preference study was based on survey data from a stratified sample of 1 752 individuals from the total Swedish population 2023. Logistic regression analyses for associations between preferences and individual, geographic, socioeconomic factors and palliative care literacy, and heterogeneity analyses are currently being performed. Longitudinal trends in place of death, 2013-19, were based on data from public and patient data registers including all deceased individuals >18 years old with a registered place of death (n=599 137), and the national register for palliative care. Logistic regression- and interaction analyses were used to investigate trends and associations between place of death and co-variables.

Results: Of all individuals, 59,8 % declared a definitive preference for receiving care at the end-of-life care in their own home, and as much as 69,8% stated that home was the definitive preferred place to die. The place of death study showed a trend towards a decrease in hospital deaths but with cross-regional variations. The total number of home deaths increased by 1,9%. In the overall population of individuals living in their own home, the likelihood of dying in hospital versus dying at home decreased (OR: 0.98, CI: 0.97–0.99). Within the home dwelling population with potential palliative needs (78,4 %), the likelihood of dying in hospital equally decreased, except in Stockholm and the north region.

Conclusion and implications: There is a major discrepancy between preferences and actual place of death among Swedish citizens. Whereas a majority prefer to be cared for and die at home, still, in 2019 only about one fifth of all individuals did so. Clearer articulation of goals and strategies related to place of death in national palliative care policy is suggested, and public health-oriented interventions aimed at strengthening resources in home care are needed.

ID: 328
Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, Policy and advocacy

Keywords: health services accessibility, neoplasms, palliative care, public health, social determinants of health

Disparate trends in place of death for people with different cancer types: a national population-based study

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Background and Purpose: This study investigated the impact of a national palliative care policy introduced in 2013. The aim was to identify longitudinal trends in place of death for people with cancer in Sweden.

Patients/Material and Methods: A population-level longitudinal trend in place of death study was performed, based on register data of all adults aged 18 or above with a cancer diagnosis as underlying cause of death, in Sweden between 2013-2019. Data were retrieved from registers at the Swedish National Board of Health and Welfare and Statistics Sweden. In addition to a more descriptive overview of place of death (hospital, home, nursing home, and other places), multivariable linear regression analyses were used to analyse trends in place of death and associated soci-demographic factors, and healthcare services and utilisation.

Results and Interpretation: Dying in hospital was most common (48.7%), followed by nursing home (25.6%) and own home (23.5%), and varied as related to sex, age, marital status, type of cancer, healthcare regions, and care at death in specialised palliative services or not. From 2013 to 2019, the total number of home deaths increased from 21.8% to 24.7%, whereas hospital deaths decreased from 49.2% to 47.1%. For people residing in their own home, there was a downward trend for dying in hospital, while no trend was detected for people residing in nursing homes. The identified trend had cross-regional variations and inconsistencies. The results point to inequity in palliative cancer care, and the need for national governance strategies.

ID: 329
Abstract Type: Poster

Topics: Death and grief literacy, Educational approaches

Keywords: death literacy, training, palliative care culture, person-centered care, intercultutural learning

Creating learning communities. Development of an international train-the-trainer course for death literacy promotion across three European countries

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Background: Death literacy includes a set of activities that aim to promote reflection and understanding related to the topic of death, dying, and bereavement. We report on the development of an international train-the-trainer course for the promotion of death literacy in three European countries (Romania, Portugal, and Austria). The aim of the course – which is part of a larger project cooperation - is to develop and implement creative educational formats to make palliative culture tangible and promote it in different contexts of society and aligned with the "Compassionate Cities" movement.

Design: The curriculum development is oriented towards the core dimensions of death literacy and teaches skills in the areas of "working with groups", "project management", "theory", and "best practices". Developing this specific train-the-trainer course curriculum, together with the participants, will enable them to create learning communities to develop palliative culture according to the dimensions of "death literacy". The course curriculum allows participants to learn from each other by sharing their different cultural heritages. The intercultural learning process between the three countries is important both at the level of the participants and at the level of the organisers/ cooperating institutions.

Methods: The course consists of five transnational modules developed in-person and videoconference sessions. Each module includes different training tools, such as meet the experts, case-based learning, team-based learning, and institutional visits. Participants are professionals with experience in the field of palliative care, with (basic) training experience. A formative evaluation accompanies the process of developing the curriculum and the course in order to gain relevant insights for further research and practice.

Results: The project is ongoing, and final results will be available at the conference. It has already become clear that specific knowledge content on palliative care has become less and less important over time. The focus shifted to intervention ideas and project management in order to empower people in different contexts in the sense of death literacy.

Practical conclusions: The project is still ongoing, but one relevant aspect could be to understand curriculum development (train-the-trainer) for promoting death literacy as an ongoing process in dialogue with the needs of different contexts and participants.

ID: 330
Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: dementia literacy, Bewusstseinsbildung, demenzfreundlicher Bezirk, Teilhabe, Selbstvertretung

On the Way to Dementia Literacy - Using the Example of the Dementia-Friendly 3rd District (Vienna)

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The dementia-friendly 3rd District was established in 2014 with the goal of developing and promoting awareness and civic engagement. Various offerings are intended to reach people with dementia and forgetfulness, as well as their relatives and companions, in a low-threshold manner. The dementia-friendly 3rd District is a growing care network centered on individuals who need guidance and counseling. Since its founding, one of the primary goals of the network partners has been sustainable awareness-raising, knowledge dissemination, destigmatization, and visibility of forgetfulness and dementia. The network is characterized by its openness to new trends and societal developments, which represents another goal. Following this objective, the "Promenz Gruppe 1030" has been part of the network since 2023.

In line with the first objective of the Österreichische Demenzstrategie (Austrian Dementia Strategy), "Ensuring participation and self-determination of those affected," representatives of the network worked together with PROMENZ between autumn 2022 and summer 2023 to implement the project "Promenz Gruppe 1030." The necessary resources for this were distributed among the network partners. The first "Promenz Gruppe 1030" was able to start in September 2023. Users benefit from both the exchange and counseling, which fosters supportive relationships, and from becoming self-advocates who speak about their condition at conferences and collaborate in working groups with Gesundheit Österreich GmbH.

In each of the regular network meetings, the network partners exchange proven practices and new ideas. Central to these considerations is the question of resources. Ideas and actions can only be implemented in small steps using the network's own resources. Implementation is done voluntarily or as an organizational contribution from the participating network organizations. Despite this, the network is growing and is committed to "Dementia Literacy," because dealing with dementia and forgetfulness must become natural. To achieve this goal, sustainable awareness-raising and knowledge dissemination at various levels, as well as the participation of those affected and the enabling of experiential knowledge in the population, are what the dementia-friendly 3rd District network tirelessly and continuously strives for.

ID: 331
Abstract Type: Workshop

Topics: Relationships and connection, Networks and compassionate communities

Keywords: Invitation; Community action, Collaborative partnerships, Systems convening

The art of invitation: convening community groups to promote participatory action learning

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University of East Anglia, United Kingdom

Target Audience: This workshop is for people seeking creative ways to involve local citizens in collaborative community-based approaches to health promotion in palliative and end of life care, including bereavement support.

Learning Objectives

Workshop participants will learn:

- a systematic and transferrable method for designing invitations to convene community groups that explicitly declare the aspirational intention of the convenor,
- a worked example of an invitation that is personalised to the participant's context that they can take away and implement, and
- an enhanced understanding of how to describe the intended experience of the group memeber, as well as being transparent about what is expected of them.

An aim to spread the Compassionate Communities movement is for organisations and individuals to identify reciprocal benefits in forging new collaborative partnerships. The importance and potential of a well-crafted invitation to bring about intended collective action is often underestimated. The art of invitation involves so much more than communicating the basic details surrounding an event or occasion. It refers to a set of skills and practices to attract, inspire, and motivate people to coalesce on a mutually beneficial theme. The intended outcome of their collective action will be to generate positive change.

To spread the principles of public health palliative care requires involvement across diverse sectors of society. When convening community-based action learning groups - the invitation initiates the collaborative process. The invitation influences group size and membership, which can mediate the success of subsequent group activities. However, community organisers can feel unsure about how to take this first step. How can we increase our confidence that the people who turn up to a community meeting are the intended people we are hoping to engage and that they are clear on the expectations we have as convenors?

In the workshop, attendees will engage in a systematic yet creative method of inviting community participation and convening groups of likeminded people around a mutual theme of interest. The skills they will learn are transferrable to other activities linked to co-production. Each workshop participant will leave with a personalised example of an invitation they can use in their unique context.

ID: 332
Abstract Type: Poster

Topics: Research methods, Care in humanitarian contexts

Keywords: care quality, care recipients, difficulties, needs, palliative care

Perceived quality, difficulties, and needs for End-of-life care at home: Perspectives of Thai patients and family caregivers

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Background: The high standard of care given to the seriously ill and their families has gained importance. Evaluation of the perceived quality of palliative care from the perspectives of care recipients, including patients and family members will lead to palliative care improvement. As far as we know, no previous research has investigated on this issue.

Objectives: of this study were to describe the level of quality of end-of-life care as perceived by bereaved family caregivers and to describe needs and problems from the perspective of patients and family caregivers during the end-of-life period at home.

Design: Mixed-methods research was employed.

Method: For the quantitative method, the samples consisted of bereaved family caregivers, who had received services from palliative care consultative centers at tertiary-level hospitals. Convenience sampling was used to recruit 480 bereaved family caregivers. The informants for the qualitative method were patients at the terminal stage of life and their family caregivers, who were purposively selected from 4 regions of Thailand. There were 60 informants per group. The research instruments consisted of demographic data sheets, quality of end-of-life care questionnaires, and interview guides. Descriptive statistics and content analyses were applied.

Results: The mean score of the perceived quality of end-of-life care was of a moderate level (M=4.01, SD=1.18). Among the 9 dimensions of the quality of end-of-life care, accessibility and use of analgesic medications (M=4.43, SD=1.27) had highest mean scores, while lowest mean scores were the dimensions of care during the loss and bereavement period (M=3.01, SD=1.62). Patients and caregivers reported several needs related to patient care at home. They mentioned difficulties in providing care for the dying at home, mainly due to a lack of knowledge and skills and financial problems.

Conclusion: This study's results highlighted that the continuity of care from hospital to home and bereavement care services need to be strengthened. In addition, programs that aim to support family caregivers' capacities to provide care for end-of-life patients at home as well as social and economic support for patients' families are strongly recommended.

Conflict of interest: No Conflict of interest

Funding: National Research Council of Thailand

ID: 333
Abstract Type: Poster

Topics: Research methods

Keywords: Strengths-based approaches, rural palliative care, appreciative inquiry, asset based, community development

Using strengths-based approaches in rural health research and their application to improving the provision of rural palliative care: A scoping review

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Background: Rural communities negotiate embedded socio-economic challenges for equitable access to health and palliative care services. These experiences are commonly expressed through 'deficit discourse' that can apportion blame and imply a deficiency in individuals or groups. In the last decade there has been increasing interest in utilising strengths-based approaches (SBAs) in research and practice. SBAs, like assets-based and community development approaches, are a fundamental shift toward working "with" communities and encourage a focus beyond simply identifying the problems to uncovering the potential of what can be.

Objectives: This scoping review explores the purpose and contexts in which SBAs have been applied in rural health research. The scoping review further explores the key components, benefits, limitations, and recommendations for future use of SBAs in rural health research to improve the provision of rural palliative care.

Design: Scoping review following the Joanna Briggs Institute methodology and relevant reporting guidelines. Data is presented in a tabular form and narrative summary.

Methods: A comprehensive search of academic databases and grey literature including published and unpublished studies, quality improvement projects, government documents and web pages. Articles were sourced using CINAHL; Medline; PsychINFO; Embase; Emcare; ProQuest Social Science; Rural; Scopus, ProQuest Dissertations and Theses Global; and Google (Australia).

Results: Reviewed articles described the use of SBAs to understand a rural health problem, or to implement a particular intervention or approach in a rural setting. This presentation provides a descriptive analysis of the SBA paradigm including the key components referencing particular methods; models or theories, the reported benefits and limitations, and recommendations for future use in rural palliative care.

Conclusion: Results from this scoping review provide valuable insights to how SBAs have been

employed in rural health research and their application to improving palliative care. The review renders the opportunity to learn from the current application of SBAs, where it has succeeded to improve outcomes for rural people, and the gaps that persist in the literature. Given the well-established inequity in rural access to palliative care services, employing SBAs in research is a unique approach to identifying positive aspects of existing palliative care provision that could be strengthened and further developed.

ID: 334

Abstract Type: Workshop

Topics: Social and structural determinants of death dying and grieving, Policy and advocacy

Keywords: Equity, palliative care, structural vulnerability

Towards equity-oriented palliative care: A pan-Canadian workshop on improvements in palliative care for individuals experiencing homelessness or vulnerable housing

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Target Audience: Palliative Care Clinicians, Social Care Providers, Researchers, Health Planners, Community Organizations serving people Homeless/Vulnerably Housing, and Volunteers

Learning Objectives:

In this workshop the participants will:

1. Learn about the genesis of, and drivers for, the development of a pan-Canadian collaborative on equity-oriented palliative care;
2. Identify barriers and develop solutions to integrate equity-oriented palliative, identifying the critical role that context assessment plays in successful implementation processes;
3. Consider lessons learned from a pan-Canadian implementation of equity-oriented palliative care, reflecting on challenges, successes, and the adaptations required to achieve equitable, safe, and high-quality care for (and with) structurally vulnerable populations;
4. Identify best practices for equity-oriented palliative care; and
5. Develop skills to become champions (or allies) in improving palliative care access and gaining access to practical tools and resources for local, national, and international implementation.

Workshop Structure

The "Improving Equity in Access to Palliative Care" (IEAPC) collaborative is a pan-Canadian initiative to improve access to palliative care for individuals experiencing homelessness or vulnerable housing. The collaborative examines equity-oriented approaches to care that address systemic and structural issues and identifies innovative practices in implementing equity-oriented palliative care for people experiencing structural vulnerabilities. The IEAPC collaborative is a four-year initiative that supports over 20 communities representing 85+ organizations across Canada to design, deliver and evaluate equity-oriented palliative care initiatives in their respective communities. Communities receive funding, access to subject matter experts, site visits to leading equity-oriented palliative care models in the country, peer-to-peer learning and collaboration, and a tailored curriculum that supports all aspects of implementation.

In this workshop we will present information about the IEAPC collaborative, sharing lessons learned, tools and resources developed, and evaluation strategies. Following didactic presentations from clinicians, researchers, educators, and health administrators, we will engage participants in interactive small group work to design equity-oriented strategies for implementation in their own communities.

ID: 335

Abstract Type: Poster

Topics: Death and grief literacy, Educational approaches

Keywords: Young people's grief, virtual education, building community capacity

Head, heart and hands - elements essential in community-focused education to support grieving young people

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Background: Since 2019, a dedicated collaboration involving colleagues from a Queensland tertiary paediatric hospital, clinicans from a state-wide, specialist paediatric palliative care service, educators from a nationally-funded palliative care education program, children's hospital charity partners, community servics from across health, education and social services, families and communities with lived experience of grieving the death of a loved one as well as the inclusion of young peoples' voices, who are supported to share their perspectives, have **all** worked together, whilst drawing upon their respective creative and practical energies to deliver an annual education event. This yearly educational opportunity has delivered an enduring and robust conversation about young people's grief.

Objectives: This free virtual event is intended to build community capacity and practical awareness of what to do when a young person experiences the death of a significant person in their life. The educational forum invites all to participate in the conversation, thereby encouraging a broad community response now, and into the future.

Design: The forum asserts that through an alliance of *head, heart and hand*, the community can be equipped to engage in conversationa about grief, and especially, when considering the needs of young people. Participants are behoved to embrace the trilogy of feelings, knowledge and actions when responding to the needs of bereaved young people. Featuring contemporary theories of grief and loss related specifically to young people, coupled with showcasing community supports, and then delivered alongside those with lived experience, a robust and comprehensive conversation about young people's grief has endured.

Methods: The yearly educational offering, delivered as a webinar, have focused upon wide-ranging topics, driven by the feedback of previous year's event attendees. Registrants are encouraged to complete pre- and post- webinar feedback via SurveyMonkey. Coupled with learnings derived from hosting educational events, and with the continued support of a committed funding body, the session has been virtually delivered with support from a professional webinar provider.

Results: Attendence grows, as well as reported positive impacts, and greater capacity and preparedness to support grieving young people.

Conclusion: This presentation will share what has been learned by event organisers in ensuring grieving young people are supported by community.

ID: 336
Abstract Type: Poster

Topics: Care in humanitarian contexts

Keywords: visiting nursing, caregiver, end-of-life care, cancer

A caregiver's coping process with the end-of-life care of a patient with cancer at home: a case study

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Background: The Japanese government is promoting end-of-life care at home. Patients with cancer experience increased symptoms and a sudden decline in activities of daily living at the end of their life, making it difficult for caregivers to cope with end-of-life care. Hence, clarifying how these caregivers cope with end-of-life care and exploring strategies for supporting them are imperative.

Objectives: To identify the coping process of a caregiver providing the end-of-life care of a patient with cancer at home.

Design: Single-case qualitative research design.

Methods: Data were obtained from the field notes and group discussions of visiting nurses and were analyzed using the Trajectory Equifinality Approach. This study was conducted with the approval of the Ethics Committee.

Results: The participant was in her 80s who worked part-time for several years and cared for her husband with advanced cancer. Her husband was in his 80s and was sometimes hospitalized to the palliative care unit for his symptoms. The caregiver wanted her husband to stay hospitalized, but he preferred to die at home. The nurses informed the caregiver of the patient's condition and prognosis at each visit. They also updated the caregiver of his monthly, weekly, and daily progress until death via a pamphlet. The caregiver observed the patient's condition and reported his distress to the nurses, which prompted them to administer continuous subcutaneous morphine injections. The patient wanted his wife to continue working, to which she obliged. The nurses visited twice a day and began long-term home-care visits. The patient died at home 4 days after starting morphine. After 10 days, the caregiver told the nurses that being able to care for the patient at home while working was wonderful. She also stated that talking to her cat soothed her and that she would assume her husband's domestic roles, such as putting away the trash and newspapers.

Conclusion: The nurses informed the caregiver of the patient's condition, and helped her cope with her husband's condition. Moreover, the nurses were able to appropriately relieve the patient's distress and increase the frequency of visits, allowing the caregiver to continue working. Such support may have helped the caregiver view the end-of-life care process positively and accept life without her husband.

ID: 338

Abstract Type: Poster

Topics: Artistic and creative approaches

Keywords: Dementia, Palliative care, Art, Cyanotype, Social Awareness

Healing light exhibition: the healing journey through dementia research

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SatiSaanti, Thailand

End-of-life and palliative care often revolve around planning and transitioning to death for individuals. Simultaneously, the emotional landscape involves navigating palliative care and pursuing one's life purpose and goals. It is crucial to recognise that palliative care is not solely relevant to older individuals; early awareness benefits all, fostering understanding of life, acceptance, and making the most of our time. Advanced dementia necessitates palliative care to ensure a dignified death, presenting challenges such as diminished decisional capacity and reliance on proxy decision-making. Stigmatisation exacerbates these difficulties, leading to rejection, discrimination, and social exclusion, necessitating concerted efforts to raise social awareness. In Thailand, fostering such awareness is crucial, and adopting an art-based approach can profoundly reshape perceptions of ageing and dementia, transcending perception barriers.

The "Healing Light Exhibition," held at the Palette Art Space in Bangkok from December 7th to December 18th, 2023, provided a platform for meaningful dialogue among diverse participants, including medical professionals, informal caregivers, artists, and students. This exhibition served as a focal point for an exploratory study aiming to examine the role of art and awareness by using cyanotype to explore Thai content. Employing autoethnography as a research approach, this study explored personal experiences to gain insights into broader cultural phenomena. Field notes and sketches were analysed thematically to uncover novel perspectives on dementia and palliative care.

The healing light exhibition centred on discussions about dementia and palliative care, highlighting individual perspectives and societal constructs of self-identity. Often overlooked in dementia care design are art's emotional and therapeutic dimensions, as designers and architects tend to prioritise physical aspects. Consequently, a gap exists between the needs of people with dementia and existing norms. Recommendations should explore various art mediums, contents, and environments to conduct therapeutic engagement, which can increase public awareness. Additionally, future research should gauge and measure the long-term impact and efficacy of innovative arts-based approaches in palliative care in Thailand.

ID: 339

Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: Old-age exclusion, social participation; deprived communities; caring communities;

Aging and social participation in deprived communities: Dimensions of exclusion and inclusion

Dzenana Pupic, Klaus Wegleitner
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Background: Caring communities and local care networks are particularly important for older adults living in deprived communities. In terms of social participation, they can empower older people to be involved more fully in community life, accessing resources and opportunities that contribute to their overall quality of life. Fostering mutual aid, solidarity, and trust among neighbors plays an important role in strengthening care relationships and social capital (Wegleitner et al., 2020), which are related to the health of older people and therefore support health promotion efforts in old age and in the last phase of life. On a socio-political level, social inclusion depends to a large extent on the design of housing conditions, both in terms of construction and in terms of how communication and community processes are moderated.

Objective: We examine what interrelations exist within and among dimensions of old age-exclusion in a deprived community in Graz, Austria. Specifically, we look at a particular form of socio-spatial old-age exclusion in a given neighborhood and examine the ways it affects other forms of old-age exclusion and shapes relationships within that community. Considerations of perspectives of intersectionality and deliberate avoidance of reproducing a narrative of aging and decline are important.

Design and methods: We use mini-narratives from the qualitative data we collected as part of a community-based participatory research project and analyze them against the backdrop of concepts of social exclusion in old age/later life (e.g., Walsh et. al. 2020, 2021).

Results: The interim findings show that while different forms of old-age exclusion can arise simultaneously, some forms may go along with increased participation. More participation on the other hand may go along with increased solidarity within the community which bears the risk of broadening exclusion through privatization of care. Additionally, older people in deprived communities may adopt exclusion avoidance strategies in which they choose the "less evil" form of exclusion. The perceived lack of solidarity from other members of community may produce grievances and lead to conflicts deteriorating social relations in the neighborhood.

Conclusions: An analysis of interrelations within and among dimensions of old-age exclusion in neighborhoods reveals how different aspects of old-age exclusion interact with each other and offers deeper understanding of this phenomenon of later life.

ID: 340

Abstract Type: Oral presentation

Topics: Relationships and connection, Networks and compassionate communities

Keywords: Indonesia, community, ethnography, palliative care, volunteer

"We are just caring for our neighbors": Improvising community-based palliative care in Jakarta, Indonesia

Hanum Atikasari
Leiden University, Netherlands, The

Background: Community-based palliative care has taken various forms globally. In Indonesia, where death and dying are not openly discussed, palliative care services are still limited and have not yet been integrated into the health system. In Jakarta, a cancer care NGO, together with local government, developed a community-based palliative care initiative by enhancing the role of community health volunteers from other public health programs.

Objectives: To explore the implementation, potential, and challenges of the community-based palliative care model in Jakarta, Indonesia, where openly discussing approaching end-of-life is generally not culturally acceptable.

Design: Ethnographic study

Methods: The study is based on eight months of ethnographic research in 2022-2023 on palliative care provision in Jakarta, the Indonesian capital, by following the activities of community health volunteers. Qualitative research methods such as participant observations, semi-structured interviews, and focus group discussions were used.

Results: This study shows how the community-based palliative care model has the potential to support the continuum of care by building on existing social and health care structures. Driven by the communal value called '*gotong royong*' (mutual support) and religious values, community health volunteers support patients in their neighborhood, although they also face logistical challenges. These challenges include lack of funding and public recognition, absences of palliative care policies and miscoordination with health workers. Furthermore, using the terms palliative care and end-of-life care can also be a challenge for some community health volunteers. One way they navigate this barrier is by saying, "We are just caring for our neighbors."

Conclusion: Fostering the community-based palliative care initiative by enhancing the existing social and health care structure can be a solution to fill a care gap to improve care services, particularly in low- and middle-income settings. However, Indonesia's community-based palliative care model shows the need to address several challenges regarding policies, funding, coordination, and to be culturally sensitive in using palliative care terminology before scaling up or implementing such initiatives in other settings.

ID: 341
Abstract Type: Oral presentation

Topics: Relationships and connection, Networks and compassionate communities

Keywords: Compassionate Communities, Personal transformation, Home Hospice, Bereaved family, Qualitative study

Personal transformation making a seed of compassion grow - a qualitative interview of a bereaved family member experienced home hospice care

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Background: Experiences of bereaved members in home hospice care are crucial factors for creating compassionate communities (CCs); in our practice, community-based home hospice care in Fukuoka, Japan, we sometimes encounter personal transformations of the bereaved members through their experiences of the end of life (EoL) care of their loved ones, which could potentially have positive impacts on spreading CCs. Some of them become to play an important role in our CCs such as a volunteer member or a healthcare provider. However, few studies have investigated how the personal transformation of the bereaved members through home hospice care is.

Objective: The aim of this study is to explore the personal transformation of the bereaved members through an EoL care with a clinic providing community-based home hospice care.

Design and Methods: We carried out a qualitative descriptive study, a semi-structured interview from one bereaved member who has been started to work with one of the facilities of our CCs as a volunteer member after the EoL care for her mother with dementia at home.

Results: The identified categories related to the bereaved person's personal transformation include 'Enjoyment of sharing the senses with others through eating', 'Changes in relationship with family' and 'Self-reflection'. The caregiver cared for her mother with respecting her love of food and entertaining others. Shortly before her mother's death, her mother, who hated to lose, told the caregiver, 'You beat me', which she took as a sign of acknowledgement of herself. However, the caregiver struggled with disagreements about her mother's care with family members who did not live with her. Self-reflection on her own care led her to obtain a qualification in care after her mother's death. She has now been involved in helping people with disabilities, valuing all five senses, and is grateful to have found a place where she was accepted, at a facility referred to her by the staff at the home hospice clinic.

Conclusion: The personal transformation of the caregiver through EoL care was consisted of the diverse changes such as self-reflection and reinforcement of values, based on experiences with people around her in her life. It can be said that the creation of diverse places and networks where bereaved members can connect at the right time and demonstrate their compassion is important for the spread of CCs in the future.

ID: 342
Abstract Type: Oral presentation

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: Death Literacy, experiences, end-of-life care, death system

Death Literacy among Dutch citizens; a survey on knowledge and skills regarding engagement in end-of-life care and support

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Background: Caring and being involved in end-of-life (EOL) care is both difficult at times as well as it sometimes becomes a learning experience. The outcome of this learning process is called death literacy. Death literacy is the knowledge and skills that people need, to make it possible to gain access to, understand, and make informed choices about EOL and death care options. People and communities with high levels of death literacy have context specific knowledge about the death system and the ability to put that knowledge into practice. There is beginning to appear some evidence that enhancing death literacy strengthens capacity for future caregiving.

Objectives: The aim of this study was to get insight in the baseline data about death literacy in the Netherlands.

Design: Next to an international validation study (with Sweden, Belgium and the Netherlands), a survey was executed in the Netherlands with the validated Dutch Death Literacy Index (DLI).

Methods: The Dutch DLI, a 29-item questionnaire with 4 subscales, and with answer options ranging from 1-5, was filled in by a sample of Dutch adults recruited from a European online panel agency. Survey responses were analysed with descriptive statistics.

Results: In total 523 respondents participated in the study. Examining all item- and (sub)scale means revealed that, relative to other (sub)scales, our respondents scored highest (mean = 3.8 | range 3.4 – 4.1) in the subscale 'Talking Support' (within main scale 'Practical Knowledge'). There were 3 (sub)scales that scored lowest (all 3 had mean 3.0), namely 'Hands On Care' (within 'Practical Knowledge') (range 2.3 – 3.8), 'Factual knowledge' (range 2.6 – 3.4) and 'Support Groups' (within 'Community Knowledge') (range 2.9 – 3.1).

Conclusion: Our survey showed that we are able to determine the current level of death literacy in a representative Dutch sample. It also showed that being able to talk about issues concerning death, dying & grief relatively feels most comfortable for the Dutch. With many other items Dutch citizens don't feel so at ease. This results helps us with targeting necessary interventions to address gaps in death literacy and/or build on existing strengths.

ID: 344
Abstract Type: Poster

Topics: The value of death, Death and grief literacy

Keywords: death literacy, end of life doulas, grief, advance planning, good death

End of life doulas and the value of death - communication, advocacy, presence

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Gentle Death Education and Planning, Australia

As the need for increased death literacy (Noonan 2016) increases globally, in tandem with an ageing population in much of the world, both assisted and unassisted deaths are being held to standards of transparency and accountability in terms of quality of life at end of life. The Lancet Commission report on the Value of Death (2022) offers a framework for considerations that point way forward for discussing and considering the notion of a 'good death', not only for the person at end of life, but also for their familes and friends. End of life doulas, non-medical support workers to the dying and their close, caring networks are uniquely positioned to enhance and improve both individual and community death literacy standards. As educators, advocates and witnesses to the preparations for end of life, active dying and (often) the immediate work of after-death body care, end of life doulas offer a compassionate presence and a well-informed, evidence-based approach to information transfer when discussing rights, options and choices at end of life. Obviously the concept of a 'good' death is highly individualised and deeply personal, and the better-informed and prepared an individual is, the higher the probability that a death that is as close to an individual's wishes as possible will take place. Good planning, which is another aspect of end of life doula work in general terms, is also highly beneficial in ensuring that options for alternate decisions are well in hand, keeping stress and unnecessary anxiety at bay during a time that may otherwise be quite challenging for both the dying and their caregivers. A well-planned end of life, coupled with thorough conversations and time spent with the person both during their end of life and immediately following death, helps avoid complex and traumatic grief for those left after their person's death, and end of life doulas are playing an increasing role in facitliating conversations with families and with communities. Based on original qualitative research with end of life doulas in four countries, the role of end of life doula, the position of death literacy for practitioners, and future directions for the field are considered with a focus on increasing both death and grief literacy in a variety of settings, including hospitals, hospices, and homes. Quotes from semi-structured interviews will be shared, casting an essential light on the work and future potential of this robust and growing international field.

ID: 345
Abstract Type: Oral presentation

Topics: The value of death, Networks and compassionate communities

Keywords: volunteering, end-of-life care, economic analysis

A benefit-cost analysis of an international hospital end-of-life care volunteer service: The iLIVE Volunteer Study

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Objectives: The aim of this study was to perform an economic analysis of the iLIVE volunteer programme, which was implemented in five hospitals in the following European countries: Norway, Slovenia, Spain, the Netherlands and the United Kingdom.

Design: To assess the expected value of the service, the economic analysis focused on assessing the cost of the service and the operational benefit-cost ratio (BCR) per country.

Methods: A costing proforma captured all relevant staff and non-staff costs of developing, implementing, and operating the volunteer service from the hospital perspective. 2021 country-specific salary costs were used, and the value of volunteer time was approximated using the opportunity cost of the average hospital nurse salary in each country. The operational BCR compared the annual value generated by volunteering with the annual operating costs. Break-even calculations determined the annual volunteer hours needed to offset operational costs and achieve a BCR of 1 in the participating countries.

Results: The implementation of the volunteer programme and related costs differed substantially between the countries. Total service development costs ranged from €3,013 in Spain to 15,829 in Norway, while operational costs standardized to one year ranged from 4,803 in the Netherlands to €41,303 in Norway. Operational BCRs ranged from 0.1 in Norway and Slovenia to 1.3 in the United Kingdom. The annual volunteer activity needed to outweigh the operational costs, assuming 20 volunteers, ranged from 5.3 hours (the Netherlands) to 54.3 hours (Norway).

Conclusion: The iLIVE volunteer programme varied widely across participating countries, with differences in volunteer supervision, staff seniority, and associated costs. Challenges posed by the COVID-19 pandemic, like restricted ward access, hindered volunteer activities and may have limited the full impact of the programme. The value analysis emphasizes the need to identify and consolidate best practices for future implementation.

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ID: 346

Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Research methods

Keywords: Community researchers, end of life care, inequalities, intersectionality, Pakistani

Community researchers in end-of-life care research addressing intersectional inequalities: A rapid realist review and evaluation

Mariam Fargin[1], Andrew Booth[2], Samina Begum[3], Inayah Sher[3], Shabina Bashir[3], Mark Clowes[2], Jamilla Hussain[1]

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A key remit of public health palliative care is to address inequalities at the end of life. However, little is known about the end-of-life experiences of intersectionally marginalised groups who experience multiple systems of power and oppression, such as racism, sexism and classism, simultaneously.

A method proposed to support greater access and inclusion of such individuals in research is to have community researchers as part of the core research team. We define community researchers as individuals with similar social identities, heritage and location to the research participants of interest. However, how best to work with community researchers in the context of structural inequalities at the end of life remains poorly understood.

Objectives: To elicit and test programme theories on how to effectively work with community researchers in end-of-life care research focussing on intersectional inequalities.

Design: Rapid realist review and evaluation.

Methods: A rapid realist review was conducted to elicit programme theories to understand what

works for whom, under what circumstances, how and why (supported by realist methods experts and an information specialist). These theories were then evaluated through a 12-month feasibility study where three Pakistani women from a structurally disadvantaged and ethnically diverse city in the UK formed part of a research team led by two women from a similar background. The community researchers co-designed the study, conducted interviews and analysed the data on the experiences of death, dying and grief of intersectionally disadvantaged Pakistani women who had not taken part in end-of-life care research previously.

Results: Three overarching programme theories will be discussed, including (i) how power was structured, acknowledged and navigated, (ii) mechanisms of inclusion of the community researchers and participants, (iii) primacy of reciprocal relationships at different levels and the tensions this posed with academic expectations, ethics procedures and structures. How the theories related to the concept of trust will also be explored.

Conclusion: Community researchers are key community assets to enable better and safer access and inclusion of intersectionally marginalised individuals in end-of-life care research. However, addressing power imbalances at multiple levels is essential to mitigate against the extractive and reductive nature of much research practice. Recommendations on how to navigate this will be shared.

ID: 347
Abstract Type: Oral presentation

Topics: Relationships and connection, Social and structural determinants of death dying and grieving

Keywords: Intersectionality, inequalities, participatory research, structural determinants, Pakistani

What matters to Pakistani women during dying, death, grief and caring at the end-of-life: an intersectional participatory study

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Background: There are known longstanding inequalities at the end of life, including for those from minoritised ethnic backgrounds, immigrants, women and those living in poverty. The experience of those who face multiple disadvantages simultaneously, however, is poorly understood. Understanding and addressing the barriers to better access to palliative care, quality of care and outcomes for those who are intersectionally disadvantaged is essential if we are to provide equitable care for those most marginalised.

Objectives: To understand the experience of death, dying, grief and caring at the end of life for Pakistani women living in structurally disadvantaged neighbourhoods in the UK.

Design: Pakistani female peer researchers with lived experience and from a similar background led the co-development of a culturally competent and inclusive in-depth interview method which prioritised relationships, reciprocity and reflexivity. The community and institutional researchers all undertook bespoke training on participatory research methods led by national experts prior to protocol development and during analysis.

Methods: 13 in-depth interviews with Pakistani women lasting between 60-120 minutes were conducted using snowball sampling. Women were identified and recruited by the community researchers, who led the interviews, translated the transcripts and analysed the data using their lived expertise, taking an intersectional theoretical lens. 11 participants had not been invited to take part in research previously, and none had taken part in end of life care research previously.

Results: Analysis is currently underway, and the final findings will be presented. Themes will explore (i) experiences of systemic, organisational and inter-personal racism, Islamophobia, sexism and classism during caring, dying, death and grief; (ii) intra-group differences in how power and disadvantage were simultaneously experienced, were dynamic, evolved over time and across generations and (iii) primacy of community, caring and spiritual presence at the end of life.

Conclusion: This in-depth exploration of the experiences of death, dying, grief and caring at the end of life for intersectionally disadvantaged Pakistani women, by such women, has explicated what and who matters most at these times and the multiple, persistent barriers to good death, dying, grief and caring as defined by them. We will discuss the importance of intersectionality from the perspectives of researchers and participants.

ID: 348
Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: volunteer, recruitment, cancer, older adults, navigation intervention

Identifying facilitators, barriers, and strategies to optimize recruitment of volunteer navigators for implementing a navigation intervention for older people with cancer and their families: a mixed-method study embedded in the international EU Navigate pragmatic randomized controlled trial

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Background: Volunteers are key stakeholders in public health palliative care. Increasingly, they have pivotal roles in implementing patient navigation interventions. Yet, so far, there is no optimal evidence-based guideline on how to recruit them to implement such programs for practice nor research.

Objectives: To identify facilitators, barriers and strategies to optimize recruitment of volunteer navigators to implement a navigation program for older people with cancer and their families in Belgium, The Netherlands, Portugal, Ireland and Italy.

Design: A mixed-method research study embedded in a pragmatic, fast-track randomized controlled trial. Per country, an estimated 55 navigators are needed, recruited by navigator coordinators. The recruitment was initiated in August 2023 and will last until September 2024.

Methods: We use participant observations of monthly online group discussions among navigator coordinators; document analyses of recruitment materials and follow-up documents; semi-structured interviews with eight navigator coordinators; and a quantitative survey for navigators. Content analyses for the qualitative data and descriptive statistical analyses for the survey data will be performed.

Results: As of February 2024, about 115 navigators in total have been recruited across the different countries. Preliminary results from two monthly discussions reveal that countries differ in recruitment approaches. For instance, there are differences in the extent to rely on local stakeholder groups, as in the extent of use of materials (e.g. leaflets). Furthermore, there are some indications that using the term “end-of-life care” in external communication can hinder recruitment. An identified facilitator is the strong presence of a volunteer culture in a country, which helps Ireland in this case to recruit many volunteers from the beginning. The final and detailed results will be available in September 2024.

Conclusion: This study will highlight facilitators and barriers, and the strategies applied to address the barriers in recruiting volunteers for EU Navigate. More data and detailed results in September 2024 will further help us identify generic and country-specific facilitators and barriers to such recruitment. Overall, this study will provide evidence-based guidelines for optimal recruitment of volunteers for community-based health interventions. These guidelines can therefore serve as a bridge between forthcoming science and the volunteers of tomorrow.

ID: 350
Abstract Type: Oral presentation

Topics: Research methods, Networks and compassionate communities

Keywords: Compassionate communities, evaluation model, public health

Feasibility of creating a general Compassionate Cities evaluation model: a tale of three cities

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Background: It is important to have a model to assess if Compassionate Cities (CC) are having the effect on the community that they are expected to have. Additionally, such model could guide the development of new CC. Although in terms of standardization and comparison, to have a single model would be ideal, due to the socioeconomic and cultural differences of each region, it is not known how feasible this would be.

Objectives: Based on the results of focus groups conducted across three diverse CC, we aim to assess the feasibility of creating a general model to guide the evaluation of already existing programs and guide the development of new ones.

Methods: With the aim of identifying potential outcomes (benefits) from CC, we conducted 14 focus groups in three cities including caregivers and other community users of the CC, health care providers, members of governmental and non-governmental organizations allied with the CC, and the coordinating group of the CC. We coded the discussions using conventional content analysis and built a list of the outcomes mentioned. Then, we put duplicates together and put together those that were similar enough to be merged into a more general one that encompassed the others.

Results: We obtained a final list of 44 outcomes. Of them, 22 were present in the three programs, 14 were present in two of the programs, and the remaining eight were present only in one of the programs. Outcomes related to the training of the general community in end-of-life topics, providing access to centralized information about where to direct people with needs, and transforming the society to be more compassionate on a daily basis, were often reported in the three cities. Examples of those that were only mentioned in one city are: "Contribute to the current social and demographic challenge" (Bern), "Make hospitals a more welcoming place" (Buenos Aires), and "Enable access to and redistribution of care supplies" (Medellin).

Conclusion: Outcomes that represent the basis of the CC initiatives were reported in the three CC. Outcomes reported in only one CC can be seen as indicators of the capacity of each health system to cover basic needs. This speaks of the possibility of creating a single model, at least among these three contexts, which could possibly be expanded to other similar ones. However, it also reflects the need that, as part of the model, there is room to evaluate other aspects specific to each community according to its context.

ID: 351
Abstract Type: Poster

Topics: Death and grief literacy, Artistic and creative approaches

Keywords: tattoos, healing, continuing bonds, grief literacy, well being

How tattoos contribute to connection and healing

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Background: Tattoos are becoming increasingly common. Healing tattoos are defined as those that people obtain to celebrate, challenge, disrupt and/or (re)claim an aspect of themselves and/or of social phenomena. Memorial tattoos are those that honor someone who has died.

Objectives: Our research program has explored healing and memorial tattoos, asking why people get tattoos and the meaning in the process, their design, and bodily placement.

Design: This narrative inquiry with individuals with tattoos included semi-structured interviews and photographs.

Methods: Interviews were audio recorded, transcribed, and analyzed thematically using continuing bonds, posttraumatic growth, and grief literacy as theoretical frameworks.

Results: Sixty-six people participated in interviews. The act of getting a tattoo was experienced as therapeutic: memorial tattoos made people feel connected to the person who had died; healing tattoos assisted in posttraumatic growth by providing an intentional process by which an individual could process stressful events. Both kinds of tattoos challenged social stigmas.

Conclusions: This program of research on tattoos contributes to expanding upon our understanding of continuing bonds, grief literacy, and how to challenge social stigma. Tattoos provide opportunities for health care practitioners to open conversations about clients' health and social history, and wellbeing.

ID: 352
Abstract Type: Poster

Topics: Death and grief literacy, Artistic and creative approaches

Keywords: Advance care planning, Death literacy, Reflection, College students, Speech

Reflection from college students after a designed interactive speech of advance care planning: A qualitative study with theme analysis by artificial intelligence

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Background: In Jan 2019, Taiwan officially approved the Patient Autonomy Law (PAL) which allows all citizens in Taiwan to make advance decisions (AD) for 5 critical conditions. According to the law, all citizens wishing to make an AD must go through official advanced care planning (ACP) performed by certified healthcare professionals (HCP). However, the public awareness is relative low especially for college students.

Objective: The objective of the study is to evaluate the reflection from college students after a designed interactive speech of advance care planning.

Design: This is a qualitative study with theme analysis by artificial intelligence.

Methods: We designed a two-hour interactive speech of advance care planning especially for college students. The program was promoted by website and all university in Taiwan could apply for the speech as long as there are more than 100 participants per speech. The speech was then provided for free by Dr. Wei-Min Chu, who is a palliative care physician and also a medical educator, for selected universities. After speech, each students was given a "reflection card" and told to leave words of reflection after the speech. We used ChatGPT by OpenAI for theme analysis of all collected reflection cards.

Results: In 2017-2018, 20 universities in Taiwan applied for the speech. A total of 2160 reflection cards were collected after the speech. The theme analysis of the students' reflections on the speech about advance care planning revealed several common themes across five identified topics, including Gratitude and Appreciation, Advance Care Planning Awareness, Emotional Reflections and Personal Growth, Acknowledgment of Healthcare Professionals and Expressions of Love and Regret.

Conclusion: The results of our study showed that a designed interactive speech of advance care planning could be an informative and motivative tool for college student to promote public awareness of advance care planning. Also, a artificial intelligence approach is useful for theme analysis.

ID: 353
Abstract Type: Poster

Topics: Policy and advocacy, Artistic and creative approaches

Keywords: palliative care, COPD, urban slums, quality of life, community-based interventions

Overcoming challenges: Palliative care delivery for COPD patients in urban slums - Lessons learned and future directions

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Fasiuddin Khan Research Foundation, Bangladesh, People's Republic of

Background: Dhaka city's rapid and unplanned urbanization has exacerbated public health challenges, particularly for COPD (Chronic Obstructive Pulmonary Disease) patients in urban slums. Providing palliative care in this context requires specialized skills, community engagement, and an understanding of local resources to alleviate suffering and improve quality of life. Thus, for patients with COPD and their families, there is a crucial need for home-based palliative care as it means the difference between receiving treatment and not receiving it.

Objectives: This study aimed to enhance the quality of life and alleviate suffering among COPD patients in urban slums through tailored palliative care interventions.

Design: Conducted a comprehensive cross-sectional study within Uttara's urban slums under Dhaka North City Corporation (DNCC), targeting COPD patients. Home-based palliative care services were extended to these individuals, employing spirometry to identify and diagnose COPD.

Methods: COPD assessment tool (CAT questionnaire) was used to gather data via oral responses from respondents belonging to 10 urban slums around the capital city Dhaka.

Results: In the study, 130 patients exhibiting chronic respiratory symptoms were primarily selected. Of those 57 were diagnosed with COPD and needed intensive palliative care services. From there, 37 patients were enrolled into the program based on spirometry assessments, identifying them with COPD or Bronchial Asthma.

From the original group a cohort of 7 semi-educated respondents were selected, belonging to 7 different slums, for follow-up interviews with a WHOQOL-BREF questionnaire. It was typical for patients to have several comorbidities. Anxiety, sadness, and depression were the most commonly reported psychological symptoms. Among the intensive intervention group, home-based palliative care had a significant impact on psycho-social and spiritual care, especially for family caregivers and neighbors.

Conclusion: Palliative care delivery by trained professionals at home significantly enhances the quality of life for COPD patients in urban slums. This underscores the need for tailored interventions addressing unique challenges in resource-limited settings. Collaborations with local NGOs and community leaders are vital for sustainable palliative care provision in urban slums. Future efforts should focus on increasing awareness, improving resource allocation, and enhancing community-based support systems.

ID: 354
Abstract Type: Oral presentation

Topics: Policy and advocacy, Networks and compassionate communities

Keywords: palliative care, Traditional Chinese Medicine (TCM), Shanghai, end-of-life-care (EOLC), developing countries

Developing an appropriate model of palliative care for mainland China: exploring the application of alternative medicine in the Shanghai model

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Background: The Shanghai model of palliative care is a pilot project aims to build a national palliative care model, which caters to the requirements of the new medical reform: 'government-led, people-centred healthcare and healthcare as a public good' and the blueprint of the Healthy China Initiative 2030: 'to cover all people, particularly older people in need'. The central government is the policy maker of the Shanghai model, while Shanghai's municipal government is the primary organiser and leader of the Shanghai model. The Shanghai model aims to build a community-based model. Community health service centres play the most important role in the Shanghai model. GPs and other health care workers provide and innovate palliative care services in the Shanghai model. This study focuses on exploring the Shanghai model of palliative care, which aims to build a community-based model and adopt Traditional Chinese Medicine (TCM) to cover all people in need.

Objectives: 1. to explore the features and evaluation of the Shanghai model from GPs' perspectives. 2. to explore the process of GPs' choice and use of alternative medicine in Shanghai model. 3. to study the feasibility of using alternative medicine in palliative care.

Design: This study chose grounded theory methodology with an analysis approach combining the grounded theory methodology and ethnography methodology.

Methods: The paper adopts the methods of in-depth qualitative interviews with 24 participants. Ethnographic content analysis was used in data analysis. Reliable reports analysed by XC and observation memos conducted by CG were selected.

Results: From this study, the ideal model depicted by GPs should satisfy clear requirements for palliative care in the context of mainland China, including rationalisation, professionalisation, and institutionalisation. The Shanghai model has not yet reached all standards. TCM, as another low-cost treatment widely accepted by end-of-life patients and as a readily available 'spare tire'. In short, there is a lack of durability in the Shanghai model.

Conclusion: If TCM is fully utilised, especially in spiritual care, the application of TCM can help to establish a needs-based palliative care model in Shanghai. The choice of TCM by service-users is not restricted by economic conditions, although affordability is an important strength of TCM in the Shanghai model. TCM can be an important tool to achieve social justice and equality in palliative care in mainland China.

ID: 355
Abstract Type: Poster

Topics: Educational approaches

Keywords: Spiritual care; Education; Burn out prevention

Can training in spiritual care improve palliative care professionals' self-care and quality of life?: A pre-post interventional study

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Background: Spiritual care is a core part of palliative care. Research has shown that inquiring about a patient's spiritual concerns has plenty of benefits. Through non-medical discussion, such inquiry allows Health care professionals (HCP) to get to know patients better and enhances HCP-patient interactions by strengthening trust. On the other hand, the scant research suggests that there are inherent difficulties in providing spiritual care.

Aim: To evaluate the effect of a spiritual care postgraduate course for palliative care professionals on professional quality of life (ProQoL), mindfulness and self-care.

Design: This pre–post interventional study with a pre-experimental design was conducted from September 2022 to November 2023.

Method: Data were collected before and after the intervention including the variables: age, gender, profession, meditation practice, mindfulness, ProQoL, and self-compassion. The intervention consisted of an online spiritual care training course, designed based on EAPC spiritual care competencies through weekly sessions over 14 months. An experiential learning model has been built to understand and accompany suffering in palliative care practice, integrating spirituality from a trans-confessional humanist paradigm. Research permission was granted by the IRB of the Autonomous University of Madrid (Spain). Multivariate analyses of variance (MANOVA) were carried out to study the effectiveness of the intervention.

Results: A total of 30 participants participated. Most were female (90%) with an age average of 48.73 years (SD 8.77); physicians (46.7%), nurses (30%), and psychologists (13.3%). 56.7% of the participants were from Spain; 16.6% from other EU countries, and 26.5% from South American countries. Significant improvements were found in ProQoL ($F(3, 25) = 6.612$, $p = 0.002$, $\eta2 = 0.442$) and self-care ($F(3, 27) = 7.024$, $p = 0.001$, $\eta2 = 0.438$), respectively. Despite the slight increase in mindfulness level, differences between the pre-post-test were not statistically significant ($F(5, 25) = 1.710$, $p = 0.255$).

Conclusion: This spiritual care training course can contribute to improving palliative care professionals' quality of life and self-care. Therefore, we suggest prospective studies concerning more long-term effects of this project in the development of spiritual care competence. Lastly, all the learning outcomes need to be practised, polished, and extended to different cultural contexts.

ID: 356
Abstract Type: Poster

Topics: Networks and compassionate communities

Keywords: telemedicine, ambulant care, video-conferencing, implementation, evaluation

Evaluation of the implementation of digital round table meetings in the palliative outpatient setting

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Background: The digitization of society is accelerating; however, palliative care (PC) has been deemed less suited for digitalization, including videoconferencing. Among others, because of the appreciation for face-to-face contact between patients and health care professionals (HCP). Particularly in Switzerland, where geographical barriers to access care are relatively small, the need for digital interventions in PC might be too small for a successful implementation. Hence, we conducted an evaluation study in conjunction with the implementation of videoconferencing for round table meetings within our PC network.

Objectives: The objectives of this study are to show the experiences of health care professionals and patients with newly introduced digital round table meetings (DRT) in terms of (a) availability and needs, (b) feasibility and practicability, (c) accessibility and (d) general experience.

Design: Evaluation study

Methods: For our study, adult patients in PC with an indication for a DRT were screened. Eligible patients were German speaking had no severe cognitive impairment, already had at least one face-to face consultation with a PC specialist, needed to be either an inpatient with discharge plans or being cared for at home or in a nursing home. The only inclusion criteria for HCP was their participation in the DRT. The goal of a DRT is anticipatory care planning within the PC network.

Results: In total 66 participants were included in the study. Eleven DRT were conducted. The response rate was 83% for HCPs and 90% for patients. The number of participants per DRT varied between 3 and 9 people. Nineteen of the HCP (46.3%) took part online. Overall, the HCPs were satisfied with the DRT, with 66.7% rating them as "rather good" or "good". The HCPs felt that the DRT added value to the outpatient care of palliative patients (five-point scale, the median 4.0 IQR (4-5)). When HCP (n=7) reported that the opportunity to interact with the patient was poorly, patients still reported that they felt that they could address their important issues.

Conclusion: The DRT were perceived as good by the HCP and patients, even if technical challenges hindered the accessibility in certain cases. DRT can be a valuable additional support to face-to-face contact in PC. We advise further implementation of the DRT in our local network, after adjusting for some of the identified implementation barriers.

ID: 357
Abstract Type: Poster

Topics: The value of death

Keywords: last days of life; needs of patients and relatives

Patients' and family members' preferences concerning the outcomes of care for the last days of life

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Patients and family members, including friends are seen as the 'unit of care' in palliative care. Best care for the dying patient, therefore, is achieved by offering optimal support for physical, psychosocial, and spiritual suffering to all persons involved in these often highly distressing situations. This study is part of a large international cohort study within the EU-funded 'iLIVE-project'.

Aim: The aim of this study was to identify, from the perspective of families and patients, what are the aspects and goals of care which are most relevant in the last days of life.

Method: We collected data on outcomes from the perspective of patients and families prospectively and longitudinally answering to the open ended question: "What aspects of care would matter the most to you if your health (or of the relative) irreversibly worsened and death neared?. For this part of the study, we included data from participants who were in the last month of their life from the Netherlands, UK, Germany, Slovenia, Switzerland, New Zealand, Norway, and Argentina.

Results: We analysed data for 108 patients, provided by 101 patients and 37 relatives. Patients were in average 70 years old (range 42 - 94), 52% were men, and over 90% had cancer. From the patients and relatives, we obtained 138 responses, which included 584 outcomes (198 unique). The most common outcome of both groups was 'having the constant companionship from family and friends', followed by 'pain management', 'being pain free', and aspects of 'personal hygiene'. Looking at each group independently, for patients, the main aspects remained as before, with the exception that 'being sedated' came before 'personal hygiene'. For families, when thinking of the patient, 'medical care with humanism' was added. When thinking of themselves, families wanted 'constant companionship to patient', 'good communication with health personnel', 'pain management', 'professional support', 'psychosocial and emotional support', and 'medical care with humanism'.

Conclusions: Our data provide an insight into the preferences from the perspective of the 'unit of care' about what matters most during the last days of life, not only with a focus on patients but also on the needs of family members. While these aspects remain the focus of professional care, they are rarely clearly voiced and requested as essential to high quality care for every dying person, in all care settings.

ID: 358

Abstract Type: Oral presentation

Topics: Research methods, Educational approaches

Keywords: education, randomized trial, primary care, teams, palliative care

Increasing generalist provider competency in early palliative care: Results from the CAPACITI education randomized controlled trial

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Background: Part of a public health approach is to operationalize early palliative care into the work of interprofessional primary care teams. Primary care providers can initiative an upstream, early palliative care approach due to their longstanding relationship with patients and families. However, evidence of the effectiveness of virtual education programs that offer practical strategies are limited.

Objectives: CAPACITI is a virtual training program for health care professionals that teaches practical tips to provide a palliative approach to care. The program consists of twelve 1-hour sessions, divided across three modules: (1) Identify and Assess; (2) Enhance Communication Skills; (3) Enhance Skills for Ongoing Care. We will report findings from the three modules.

Methods: A randomized controlled trial evaluating two modes of CAPACITI program delivery: 1) self-directed learning (only online materials); and 2) facilitated learning (live webinars and discussion). Outcomes included: 1) Percent of patients identified as requiring palliative care (past 3 months), 2) Timing of reported initiation of palliative care, and 2) Self-reported palliative care competency (End-of-Life Professional Caregiver Survey [EPCS] / CAPACITI Competency Survey). Analyses consisted of differences between intervention groups in pre/post paired comparisons and examination of covariates.

Results: Of the 566 participants across Canada that enrolled in CAPACITI, 380 (67%) completed Module 1 and 230 (41%) completed the full program (Modules 1-3). Participants represented diverse interprofessional backgrounds. At baseline, 295 providers (paired pre/post) reported identifying 4009 patients requiring palliative care, compared to 5358 patients following the intervention, an increase of 1349 patients (7.2 percentage points on average). Although there was a significant increase in patients identified overall (Paired Sample T-Test, $p<0.001$), no difference was found between the self-directed and facilitated groups, post intervention (GLM, $p=0.3$). Providers' EPCS competencies improved overall (Paired T, $p<0.001$), with no significant difference between the groups (Cochran–Armitage trend test, $p=0.27$).

Conclusions: CAPACITI improved self-assessed palliative care identification and provider confidence in key competencies, regardless of whether the education delivery was self-directed or facilitated.

ID: 361

Abstract Type: Workshop

Topics: Educational approaches, Artistic and creative approaches

Keywords: public, patients and families, early palliative care, communication, education, empowerment, activation, caregivers

Successful public messaging about early palliative care: The 7 keys of the Waiting Room Revolution

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Description: In 2021, Drs. Winemaker and Seow created a public health palliative care social movement called The Waiting Room Revolution, which is designed to make a palliative care approach accessible to all patients and families early in their illness journey. (www.waitingroom-revolution.com) The heart of the movement is to activate patients and families, early in their life-changing illness, to take charge and control of information.

The movement has different communication strategies including social media, a podcast and a book. The movement has achieved several milestones of success: The podcast is ranked in the top 1.5% of global podcasts, has over 100K downloads, and is listened to in 82 countries. The book was a #1 best-seller in it first month of release.

Dr. Seow will share the lessons learned in messaging about palliative care to the general public, patients and families, including the resulting 7 keys that can activate patients, families, and providers to have a better illness journey. He will also share the 7 actions for providers that correspond to the 7 keys for patients. The workshop will discuss the applicability of these 7 keys to other countries and strategies for spread.

Target audience: All health care providers and palliative care educators

Learning objectives

1. Share the lessons learned of how the Waiting Room Revolution evolved into a successful social movement
2. Describe the 7 keys for navigating a life-changing diagnosis for patients and families
3. Apply 7 corresponding actions for providers to embody an early palliative care approach

Structure of the workshop

The format of the 1.5 hour timeframe:

- 30 mins of explaining the approach and the 7 keys for navigating a life-changing diagnosis
- 30 min of using practical exercises to role play the different skills and exercises taught to the public and to generalist providers
- 30 mins of discussion of how these approaches can be adapted to different international contexts

ID: 362

Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: organization, leadership, change management, compassionate city

Sisyphos goes compassionate – the need for structure and leadership in a compassionate city

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Background: developing compassionate cities is of utmost importance especially in high-income industrialized countries because of sociodemographic change and shortage in health care personnel. Various strategies apply how to activate organisations and the public to engage in this topic: good examples exist for both, bottom-up and top-down approaches.

Aim: this abstract summarizes experiences from the perspective of organizers and drivers of a compassionate city in Switzerland in order to inform others about potential essential factors for generating impact in this field.

Method: retrospective analysis of steering group protocols.

Results: we analysed steering group protocols from 2016 to 2022. Strategic considerations on the development of a compassionate city started in 2016 inspired by a similar process in the Eastern part of Switzerland. The project was initially co-lead by the head of the local palliative care centre and the lord major of the city and his city administration representative. Later, other organizations from NGOs and public institutions joined in. Leadership issues arose early and repeatedly over these seven years: responsibilities for events and fundraising, rules/ rights in an unstructured collaboration, strategic decisions e.g. in regard of cooperation between and inclusiveness of professional organisations in the field including volunteers, and who is best in representing the different perspectives and needs of the public and health care professionals. Even after years and many successful public events, the group still favours an informal collaborative network without clear organisation and a common access point. Changes of representatives within the steering group led to repeated discussions on

vision and mission and to a permanent restart of team performing processes.

Conclusion: Regardless of how democratically a network wants to be run, it seems to need a clear strategy/orientation and a legal form. The core team must be clear about the goal and purpose, a shared visibility/contact point, a website and active member marketing that can integrate motivated stakeholders. Successful fundraising requires clear non-profit orientation. Driven by compassion alone, the idea of a compassionate city does not lack attraction and inspiration, but impact, and activists may feel like Sisyphos.

ID: 363
Abstract Type: Poster

Topics: Death and grief literacy, Artistic and creative approaches

Keywords: Death, schoolage children, story, Delphi method.

"If death was told to me" or youth literature as a creative mean to apprehending death

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Background: Throughout their development, children will experience various losses, such as the death of a pet or of a grandparent. However, the acquisition of the concept of death, in its five dimensions of universality, irreversibility, cessation, inevitability and causality (Slaughter et Griffiths, 2007), varies according to factors such as developmental stage, experiences of death in the family and upbringing, and family, school, religious and cultural influences (MIller, 2018; Whalen et al., 2015). Even if between the ages of 9 and 11, the concept of death is generally really understood and integrated (D'Antonio, 2011), many parents and caregivers of children aged between 5 and 12 do not know how to appropriately approach this potentially delicate subject with them.

Objectives: This paper will present the results of the first step of pilot a study aiming at obtaining expert consensus on the content and form of the French story "Grandpa Mario's Death" (La mort de grand-papa Mario), written by Anne-Marie Lebrun, psychoeducator, to address death with children aged 5 to 12.

Design: Inspired by the Delphi method, the study consisted of the following three phases: 1) literature review, 2) adaptation of the story and 3) validation using the Delphi method (Keeney et al., 2011).

Methods: After having conducted the first phase (literature reivew), we concluded that dimensions of universality, irreversibility, cessation, inevitability and causality should be included in the story. To adapt the story (second phase), wo research assistant independdly read the story, completed an interjusdge agreement regarding aspects that should be revised and/or submitted to the consensus of experts. For the third and last phase, two rounds of Delphi have been conducted with three categories of experts: 1) parents of children aged 5 to 12, 2) child development specialists and 3) psychosocial workers having experience with this age group as to obtain consensus onthe content and the form of the story.

Results: The final story as validated by the various experts will be presented, with a particular emphasis on the elements where consensus was easily and challenging to obtain.

Conclusion: Apprehending the death with schoolage children is often reported as challenging. Using a story validated by experts such as "Grandpa Mario's Death" is therefore an innovative and inspiring initiative which future implications will be discussed.

ID: 364
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, Networks and compassionate communities

Keywords: Palliative Care, Dementia Care, Community Care, Network, Hard to reach

Palliative and community care network

Elisabeth Reitinger, Katharina Heimerl, Gert Dressel, Ilona Wenger
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With our contribution we want to participate in the exchange of experiences from compassionate cities in German-speaking countries (Germany, Austria, Switzerland, D/A/CH).

How can people at the end of life who live alone at home be well supported and cared for? How can people with forgetfulness and disorientation be helped to find their way around in everyday life? Who looks after those who are socially and economically disadvantaged or socially marginalised?

How can we, how can society contribute to ensuring that marginalised groups are not forgotten?

These are questions that lie at the interface between palliative care and community care. In order to address these questions, we have set up a network in the German-speaking world, departing from the Institute of Nursing Science at the University of Vienna. Together with the network, we have started a writing project focusing on the question: "Social participation - how to include >hard-to-reach< groups"?

In this volume, the personal and professional experiences and expertise of the members of the network will each shed light on one or more specific aspects of the issue of social participation of hard-to-reach groups. Telling and sharing these with each other - also in writing - supports and promotes mutual understanding.

The network has so far met 5 times online in half-day moderated networking workshops. A first meeting in person is planned for Fri 18 October 2024 in Vienna. The joint publication will be presented there and the further network process will be decided.

ID: 365
Abstract Type: Poster

Topics: Educational approaches, Artistic and creative approaches

Keywords: public, patients and families, early palliative care, communication, education, empowerment, activation, caregivers

Public-facing education of an early palliative care approach: Impacts of the Waiting Room Revolution social movement

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Background: Health Canada has a public education campaign to support early palliative care. They partnered with The Waiting Room Revolution, which is a social movement designed to activate patients and families to leech out an early palliative care approach without the labels. It focuses on teaching patients and families 7 keys to apply early in a life-changing diagnosis to increase hope, preparedness, choice and control.

Objectives: To describe, evaluate, and synthesize learnings from a public campaign of the Waiting Room Revolution, in partnership with Health Canada. This includes multiple public-facing events, in partnership with diverse organizations, to the public.

Design: During January 2024 - September 2024, we will embark on dozens of public-facing events to describe the 7 keys of the Waiting Room Revolution. They are targeted to the public, patients, families, and community organizations and providers. During that time, we will also be co-designing several disease-specific roadmaps with patients, families, and providers to encourage seeking information early in an illness.

Methods: To evaluate the impact on the understanding of palliative care due to the events, we will collect evaluation data about perceptions of palliative care, advance care planning, and the need for patient and family activations. We will collect audience questions and reactions. For the co-designed disease-specific roadmaps, we will develop prototypes and conduct qualitative interviews with patients, families, and providers, to arrive at a final version of the tools.

Results: We will share organizations we partnered with, # of attendees, the main questions and reactions, and our key learnings. We will also share the results of the evaluation questions. For the patient-facing tools we co-designed, we will describe the changes made from the prototypes due to feedback from patients, families, and providers, and share the final version of the tool(s), their key features and the rationale behind them.

Conclusions: So far, the public reaction to The Waiting Room Revolution has been incredible. It is a complement to public health palliative care strategies, such as Death Cafes, as this targets patients and families facing a life-changing diagnosis presently. Understanding the messages that the public successfully respond to and are motivated to implement is an important part of achieving PHPCI mission.

ID: 366
Abstract Type: Oral presentation

Topics: Social and structural determinants of death dying and grieving, The value of death

Keywords: good death, social and cultural dimension, value

The meaning of good death among Thai people

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Mahidol University, Thailand

Background: Good death is often subjective and can vary across cultures, religions, and individual beliefs.

Objectives: This research aims to explore the meaning of the death and good death among Thai people.

Design and Methods: The study used qualitative approach, using in-depth interviews with purposive sampling of 25 person. The respondents included both men and women aged 40-60 years from four regions of Thailand. The analysis was employed by content analysis.

Result: The socio-cultural dimension of a good death among Thai people encompasses a broad range of factors, including holistic well-being, the meaning of life, interpersonal relationships, cosmological beliefs, and the absence of suffering. This multidimensional approach reflects the complexity of the human experience and highlights the importance of cultural context in shaping perceptions of a good death. Good death means beyond free from physical pain and symptoms management but also the meaning of life, the interpersonal relationship, both in this world and the next world, and in relation with their cosmology. The meaning of life is intertwined with the idea of a good death. It implies that a meaningful life contributes to a good death. This connection emphasizes the importance of purpose and fulfillment throughout one's existence. The good death is the result of good Kama, having dignity and a sense of completion and of the timing of one's death. The quality of relationships, both in the present life and the afterlife, is a crucial element of a good death. This implies that connections with others play a significant role in the overall well-being of an individual as they approach the end of life.

Conclusion: The concept of a good death is not solely about physical health but includes mental, spiritual, and social aspects. This suggests a more comprehensive view of well-being that considers the person as a whole. Recommendation from the research is to promote good death during the end of life care with considerations of cultural value and cultural contexts of the persons.

ID: 367
Abstract Type: Poster

Topics: Educational approaches

Keywords: primary palliative care, palliative care, assessment, PCKT

Assessment of primary care physician knowledge on primary palliative care competencies

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Background: Palliative care is interdisciplinary care that focuses on improving the quality of life of patients diagnosed with terminal illnesses. Primary palliative care differs from sub-specialist palliative care in that primary palliative care is conducted by primary care physicians who integrate palliative care into their clinical practice. The goal of primary palliative care is to bridge the gap between primary care physicians and palliative care subspecialists so the patient can receive basic palliative care services. Current research in this area suggests that primary care physicians' knowledge of primary palliative care is lacking.

Objectives: This study aims to evaluate American primary care physicians' level of knowledge regarding primary palliative care.

Design: This cross-sectional study used a validated digital survey, the Palliative Care Knowledge Test (PCKT), to determine physicians' level of knowledge regarding primary palliative care. The domains included on the PCKT include philosophy, pain, dyspnea, psychiatric problems, and gastrointestinal issues.

Methods: The inclusion criteria for participants were that they must be English-speaking primary care physicians (family practice physicians, internal medicine physicians, and psychiatrists) in the United States.

Results: The survey was distributed to 3,221 primary care physicians in the United States. 53 responses were generated, resulting in a response rate of 1.3%. The average score for the philosophy category was 92% with a standard deviation of 21%. For pain, the average score was 70% with a standard deviation of 16%. For dyspnea, 85% with a standard deviation of 19%. The average score for psychiatric was 52% with a standard deviation of 22%. Lastly, the average score for GI was 71% with a standard deviation of 22%.

Conclusion: This study identified areas of primary palliative care in which primary care physician knowledge was lacking. Subsequent studies that take measures to increase response rate could provide valuable information about the current state of primary palliative care education. This data could be used to create a curriculum that could be integrated into medical training.

Funding: Special thanks to UCF Office of the Associate Dean for Faculty and Academic Affairs for funding this study.

ID: 368
Abstract Type: Oral presentation

Topics: Relationships and connection

Keywords: end of life doulas, community end of life care

Reciprocal benefits of including end of life doulas in community palliative care: learning from pilot projects in the UK

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Background: For countries that have an ageing population with increasingly complex needs at the end of life at a time when the financial cost of providing end of life care is increasing, there is an urgent need for innovative ways of providing community palliative care to be developed. End of life doulas provide non-medical practical, emotional, and (if desired) spiritual support to individuals at the end of life and those important to them.

Objectives: In the UK a number of forward-thinking National Health Service (NHS) commissioning bodies have piloted the use of end of life doulas alongside existing community palliative care services with the objective of assessing whether such an approach can reduce hospital admissions in the last weeks of life, improve the quality of advance care planning, increase the percentage of patients dying in their preferred place of death, improve informal carer wellbeing and reduce pressure on existing health and social care services.

Design: Two pilot projects in Leeds and London, UK, are being evaluated using a mixed-methods approach

Methods: Evaluation involves the use of focus groups, semi-structured interviews, quantitative data collection relating to number of hospital admissions, advance care plans and preferred place of death, and an online survey for friends and relatives of the patient. One project is using contribution analysis which includes qualitative data collection from end of life doulas working on the project.

Results: Evaluation is in progress however early results suggest that end of life doula support can result in lower rates of hospital admission in the last weeks of life and improved informal carer wellbeing. There is also evidence that the end of life doula service reduces pressure in other areas of the health service for example community assessment teams and General Practitioners (GPs). Full evaluation results will be available by October 2024.

Conclusions: The use of end of life doulas to work alongside existing health and social care services can improve the quality of care for patients dying in the community, improve informal carer wellbeing and have reciprocal benefits for end of life doula and existing healthcare services. If commissioning bodies can surpass risk aversion to trial end of life doula approaches in the community this can help achieve the aims shared by all palliative care services of providing end of life care which aligns with the patient's wishes.

ID: 369
Abstract Type: Oral presentation

Topics: Networks and compassionate communities, Educational approaches

Keywords: physician training; community healthcare; palliative medicine

Confessions of a palliative medicine physician; I left the community behind

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Palliative Medicine, is a robust, competency based, accredited field of medicine whose very genesis was organic and gradually emergent just over the last 40 years. Despite the incredible contributions Palliative medicine has made to evidence based, person centred care for people approaching the end of life, attention to the community itself has often not been one if its pillars.

In this unique presentation, an academic physician and focused practice professor of palliative medicine nearing the end of her career, will participate in a frank dialogue-interview style-with a social media based influencer in public health palliative care. Together they will identify both the conscious and often unconscious drivers that influenced a generation of palliative medicine clinicians. Uncomfortable realities of how doctors are socialized and trained will be identified and the real, albeit unintended consequences of evidence based biomedical training in healthcare will be named.

This first person account will focus on the lived and learned experience of this leader in palliative care and how a mid/late career jolt enabled a humble pivot that helped reframe training and competencies in palliative medicine to "re-imbrace" community. Lessons learned and importantly, future directions will be highlighted.

ID: 371

Abstract Type: Oral presentation

Topics: Policy and advocacy, Networks and compassionate communities

Keywords: family carers, patient experience, access, involvement, communication

Understanding the care received at the end of life through a family carer lens: analysis of free-text responses from a national post-bereavement survey in England and Wales

Joanna Goodrich[1], *Sophie Pask*[2], *Therese Johansson*[1], *Ikumi Okamoto*[3], *Lucy Budd*[1], *Stephen Barclay*[3], *Fliss EM Murtagh*[2], *Katherine E Sleeman*[1]

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Background: Family carers are a main provider of care at the end of life. It is essential to understand their experiences, the aspects of care that are most important to them, and what makes a difference.

Objective: To understand the care provided to patients near the end of life through the experiences of family carers.

Design: A nationally representative cross-sectional post-bereavement survey.

Methods: The survey was administered via the Office of National Statistics to 3,000 people in England and Wales who had registered the death of a family member 6 to 10 months previously. Respondents were asked to reflect on care their relative received in the last 3 months and last week of life, the circumstances of their relative's death, their own experiences of care, and bereavement. Free-text responses were analysed using thematic analysis.

Results: 1179 people responded; 1048 (89%) provided free-text comments. Three themes were identified:

1. *Novelty of caring and preparedness:* Overwhelmingly, a majority of care fell to family and friends. For many, this was their first time caring for someone at the end of life. Few knew what kind of support to expect, and how to find it. They often felt-ill equipped to provide care, in terms of confidence and competence, which led to issues around feeling safe and patient safety.
2. *Accessing and navigating healthcare:* Obtaining the necessary information and identifying the 'right' person to help was hampered by difficulties with navigating different services, poor communication, and long waiting times. Family carers described a mismatch between their expectations and reality. Challenges with accessing support from primary care services was particularly noted. The time consumed by these activities was time they wanted to spend with their dying relative and added to the caring work they were already doing.
3. *Being left out of the care loop:* Family carers often felt unsupported and unheard by health and care professionals. They wanted to feel involved in decision-making and that their knowledge of the patient was respected by clinicians.

Conclusion: These data highlight aspects of care at the end of life that are important to family carers identified from their own experiences. The unpreparedness of family carers is an important public health issue, as they feel unsupported and let down (especially by community-based services) and unsafe. Clearer information that sets expectations of what is available is imperative.

ID: 372

Abstract Type: Oral presentation

Topics: Death and grief literacy

Keywords: Death Literacy, Old age, Migration

"Living well until the end" - promoting death literacy for older people with a migration biography and/or a precarious socio-economic background

Anna-Christina Kainradl, Klaus Wegleitner

University of Graz, Austria

Background: The health opportunities and health literacy of older people with a migration biography and/or a precarious socio-economic background are shaped by intersectional dynamics of marginalization and discrimination. The perspectives of this population group are underrepresented, their information needs regarding the topics of grief, death and dying are insufficiently addressed.

Objectives: In the context of a community development process in an urban housing project, we therefore addressed the question of how dialogue and communication formats need to be designed in order to talk with this population group about grief, death and dying and thus contribute to strengthening their death literacy. The aim was to give more space to the perspectives of older people themselves and to create spaces for dialogue and understanding about questions of living well until the end.

Design: A participatory living lab process in a local urban community was used to address residents expressed needs for places to meet and share around issues of grief, death and dying.

Methods: Inspired by the methodological approaches of storytelling cafés, philosophical practice and last-aid formats, a dialogue format with an integrated knowledge impulse was developed, implemented and reflectively evaluated in cooperation with experts from a hospice for homeless people and from social work.

Results: The design and setting of "Living well until the end" focused on everyday experiences of caring and ways of dealing with grief, death and dying. The setting enabled the exchange of knowledge about existing care networks and the acquisition of new knowledge. When preparing the topics and conducting the discussions, it was particularly important to combine social space and lifeworld-related concepts with geragogical considerations (e.g. through the choice of the location and by focusing on the everyday habits of social exchange and communication).

Conclusion: The development, implementation and evaluation of "Living well until the end" provided insights into the methodological design of such an event for this population group (e.g. designing the discussion as an everyday table talk; moderation with a stronger advocacy approach) as well as the ideas and experiences of older people with a migration biography and/or living in precarious socio-economic circumstances. Joint reflection and negotiation processes were encouraged, which also helped to strengthen the sense of community and to promote death literacy.

ID: 373
Abstract Type: Poster

Topics: Educational approaches

Keywords: Palliative Care, Nephrology, Kidney Supportive Care

Integration of Palliative Care in Nephrology: A benefit for patients and relatives as well as economically. What we can learn from Australia

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Background: Kidney Supportive Care (KSC) is an important part of healthcare for patients living with chronic kidney disease. International studies show a benefit in symptom management, Advance Care Planning, family support and death preparation. KSC is well established in Australia. Most palliative care clinics operate as an extra layer of care rather than an alternative to nephrology services. They provide multidisciplinary support to patients on kidney replacement pathways, including those awaiting transplantation as well as patients for whom conservative kidney care is most appropriate. In Australia, specialist KSC services have operated for around two decades, and patient related outcomes including improved quality of life and increased survival have been demonstrated. By avoiding dialysis that may not have been delivering better patient outcomes, healthcare costs can be reduced to a large extent. Such a standardized program does not yet exist in Switzerland.

Objectives: To show the different stages of integration of palliative care in a medical speciality such as Nephrology by comparing one Australian model of care and the situation in Switzerland.

Design: Descriptive study

Methods: Case-oriented, mainly qualitative comparative method between the KSC care model of an Australian institution and the situation in Switzerland.

Results: In Australia, palliative care is already successfully involved as an accompanying discipline within the KSC. The latest data of how

KSC can influence symptom management, Advance Care Planning, Family Support, Patient and Family Education, Lifestyle and Bereavement Support and above all how economically successful it can be will be presented at the congress.

Conclusion: Internationally, the integration of palliative care in specialist medical disciplines is already much further advanced than in Switzerland. KSC is not only a success on a personal level but also economically and should therefore be introduced here in Switzerland.

ID: 374
Abstract Type: Oral presentation

Topics: Relationships and connection, Networks and compassionate communities

Keywords: Relationships, Compassionate Communities, life limiting illness, qualitative research, support networks

Relationships while living with life limiting illness: What can Compassionate Communities offer?

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Background: Life limiting illness is managed in the context of complex social networks, with social support and connectivity linked to positive health outcomes. Yet those living with life limiting illness often experience the breakdown of personal relationships, social isolation and the loss of community mobility. This disturbance ripples out, impacting the relationships and networks that the person with life limiting illness is situated within. In response, a Scottish hospice has been supporting a Compassionate Communities approach in several ways; from developing community-led cafes; employing a team of professionals; supporting volunteer befrienders, and through asset-based community development activity. Yet little is known about how, and to what affect, this approach is experienced by those affected by life limiting illness and informal and formal caregivers.

Aims: The objectives of this doctorate study are twofold; to understand how life limiting illness impacts relationships and connectivity to community, and to explore what a Compassionate Communities model in the context of a Scottish Hospice can offer to those relational experiences.

Methods: A qualitative multimethod case study approach was adopted. Methods of individual interviews, dyadic interviews, and the creative method of photovoice were used with those living with life limiting illness and their self-selected relational network. Group interviews were also conducted with Hospice staff.

Findings: Within case and across case analysis show that illness impacts participants notions of what it is to be living (giving help, having purpose, and maintaining independence). This in turn impacts one's ability to access and maintain social connectivity to social networks. Compassionate Communities activities reinstates elements of what it is to be living; by building confidence and allowing participants to engage in positive altruistic roles. Suggestions of future improvements of Compassionate Communities, such as addressing the relational dynamics between volunteers and those they support.

Conclusion: This doctoral research captures the personal and relational complexity of living with life limiting illness in Scotland today. In the context of this research, a Compassionate Communities approach is not without its challenges, yet it offers a variety of relational mechanisms which provide those living with life limiting illness and their relational network a means to reconstruct the social self.

ID: 375
Abstract Type: Poster

Topics: Death and grief literacy, Networks and compassionate communities

Keywords: Supporting, health- grief- deathliteracy, positive health

'De Kolibrie', a compassionate place

Ria Plasschaert

Carevita VZW, Belgium

Idea: "De Kolibrie", established in 2016, is literally an open house where people facing a chronic illness - as patients or in their immediate environment - can walk in to share their stories with a trained volunteer. They can also take part in a diverse range of activities based on positive health. Our goals are:

- Increasing empowerment
- Improving quality of life

- Increasing their knowledge about their specific challenge
- Supporting people in the acceptance process, coping with grief and loss
- Improving health, grief and death literacy
- Preparing for and learning to cope with the last phase of life and its impact on day-to-day life

We believe it is important that everyone can enjoy "De Kolibrie" regardless of their financial means, so we provide our activities free of charge. Donations and free contributions are the only source of income to support our operation. We are therefore a purely volunteer organisation that receives no structural support. Our team dedicates itself voluntarily day after day for free. By partnering with other organisations we are expanding our impact and strengthening the network of support essential for the well-being of our community.

Implementation: We offer a wide range of activities including

- leif-sessions (leif is the abbreviation of End-of-Life Information Forum): intimate conversations in which individuals, couples or families - supported by leifcounsellors - can discuss, share and record their wishes and concerns around the end of life.
- Sessions around grief counselling that go beyond individual support. Here, on the one hand, we have the set of 6 pre-structured workshops where we provide methodologies and the free groups. By offering group sessions, we try to create a platform where participants can support each other and make connections with others going through similar experiences.
- Where appropriate, we involve family members, friends and neighbours in individual end-of-life support. In this way, we aim to strengthen the support network and try to create a warm environment where no one needs to be alone during this delicate stage of life.

Conclusions:

- About 2,700 visits per year
- Approximately unique 310 visitors per year, with our guests being referred by doctors, other local health partners and word-of-mouth
- Positive results on satisfaction surveys

Our numbers prove that initiatives like ours are much needed and add value within local communities.

ID: 376
Abstract Type: Workshop

Topics: Relationships and connection, Care in humanitarian contexts

Keywords: humility, compassion, co-design, palliative care, humanitarian

Connecting communities in palliative care: Using a design science approach for co-developing humility guidance

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Rebecca Wright[5]

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Target audience:

About us: We are a group of palliative care practitioners, researchers and community members from different backgrounds, working with diverse populations. Our work spans people experiencing humanitarian crisis, homelessness and substance abuse, and those often marginalized in access to care including LGBQTIA+ and ethnically diverse communities.

We connected through shared experiences of partnering with, and learning from, different populations in how people and communities want to be seen and cared for, elements that are often lost in a quest for palliative care specialization and standardization. We found mutual connection in understanding our role as guests, witnesses and learners, not experts and teachers, to illness suffering and caring. We hold a common ambition to center compassion and humility in caring and research practice.

Our process: We have begun a process in collaboration with our research partners, using a design science approach, of collating and translating our observations, stories, and lessons into explicit guidance for palliative care practice and research that is compassionate and humble in conception and delivery.

Our invitation: We invite all those looking to reimagine and refocus palliative care practice and research towards genuine partnerships and human connection to contribute to the design of a Humility Reflection Guidance and be future partners with us in this endeavor.

Learning objectives:

1. Provide a forum for sharing stories, perspectives, and lessons on connection, compassion and humility in palliative care practice and research across diverse communities and populations.
2. Use a design science approach to extract explicit principles from implicit knowledge and experience, to build and develop consensus around a Humility Reflection Guidance amongst workshop participants.

Structure of the workshop:

1. Presentations on palliative care across marginalized populations and diverse settings, with researcher perspectives on what we have learned, how we have been personally changed by the people and communities with whom we have worked, and the common threads across our work.
2. Description of the design process to draft a Humility Reflection Guidance.
3. Facilitated group discussion using a design science approach to build consensus on a Humility Reflection Guidance.

After the conference, we will finalize and share the guidance with participants for review, with a plan for wider dissemination of our conclusions.

ID: 377
Abstract Type: Poster

Topics: Policy and advocacy

Keywords: MAID, suicide, euthanasia, legislation, epidemiology

Public Health Issues Raised by legal Assisted Dying (AD). Does legal assisted dying increase (by contagion) or decrease (by prevention) suicide rates?

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Background: and objective According to one view, legalised assisted dying (AD) would increase the prevalence of general, often tragic, suicide by signaling approval of suicide ("contagion"). Conversely it would be decreased through shifts from traumatic general suicides to harmonious AD ("substitution or prevention"). While no "contagion" evidence is extant, only anecdotal reports from the Benelux countries suggest that the mere possibility of AD can prevent (attempted) suicides. Switzerland, the Netherlands and Belgium have the oldest laws permitting AD for both terminal and non-terminal pâtients with unrelievable suffering, thus providing an opportunity to test the competing views by comparisons with non-permissive jurisdictions.

Methods: In European jurisdictions with legal AD, using statutory longitudinal data for per capita general suicide and AD, we compare the trends in their respective prevalences. Trends in of general suicide in AD-permissive and neighbouring non-AD permissive jurisdictions are then compared. Confounding factors are considered.

Results: In Belgium and Switzerland (with high baseline general suicide rates), between 2000 and 2019 the rate dropped around 30%. In the Netherlands (with low baseline rates), it rose around 10%. Comparisons with neighbouring non-AD jurisdictions made interpretation more complicated. Important confounding factors could not be adequately controlled.

Conclusions: No consistent pattern emerges. Legal AD can at this stage not be shown to promote contagion or prevent suicide. Expected additional data from the Dutch and French-speaking halves of Belgium, with widely different rates of AD within a same jurisdiction, may shed more light on the issue.

ID: 379
Abstract Type: Oral presentation

Topics: Care in humanitarian contexts

Keywords: refugees, ambiguous loss, grief, trauma, disenfranchised loss

Refugee and migrant populations: primary and secondary loss and disenfranchisement examined through a case study

Janet McCord

Edgewood College, United States of America

The notion of ambiguous loss is anchored in Pauline Boss's family experience of immigration to the United States in 1929. In her theory, she notes there are two types of ambiguous loss: where there is a physical absence with psychological presence (such as a person who has been "disappeared"), and where there is a psychological absence with physical presence (such as dementia). This presentation will focus on the first type of ambiguous loss where there is physical absence with psychological presence: the physical loss of someone that may remain unverified and may be without resolution, but for which memories can serve as a psychological presence of the missing individual. The role of secondary losses, such as communities, patriotic identity, and assumptive world, will be considered.

Over 89 million people have been forcibly displaced as of 2021, including 36.5 million below age 18. All share a struggle with ambiguous grief and loss that is just beginning to be studied. For refugees, ambiguous loss is often characterized by hopes for refuge, longing for the past, and an endless sense of loss. This presentation will examine what one example of forced displacement looked like, and how refugee experiences can be conceptualized.

It will then turn to the stories of refugees, in particular Sudanese youth living in Michigan known as the Lost Boys, and their ways of coping with the ambiguous loss of living apart from families and culture. To survive and thrive, these youth drew on relationships with peers, the presence of elders as a created surrogate family structure, and the psychological presence of their parents through remembering life lessons.

Finally, tips for supporting refugee families will be discussed.

ID: 380
Abstract Type: Oral presentation

Topics: The value of death, Artistic and creative approaches

Keywords: community, creative, participatory, place-based; system-change

Creativity, participation and change: designing community workshops to share the ideas of the Lancet Commission on the Value of Death

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The Lancet Commission on the Value of Death (2022) set out 5 principles and many recommendations to improve people's experiences of dying/grief through major cultural and system change. However, this will only become reality if people in local communities engage with these ideas and develop their own locally-based actions.

This project is to test a series of workshops using participatory and creative methods to introduce the Lancet Commission concepts to community participants with no prior specialist knowledge, in ways that can stimulate ideas for change and community action.

The project uses a Participatory Action Research approach, with place-based participant sourcing in a city in Southern England. A range of methods are being used with intention to create accessible, enjoyable ways for participants to engage with Lancet Commission concepts, including:

- Short expert videos to introduce the 5 principles of a Realistic Utopia and stimulate response
- Facilitated conversations
- Collective collaging to explore structural determinants of death, dying and grief
- Stone-painting, placement and (re)arrangement to explore death systems
- Nature connection
- 'If.. Then.. And' statements
- Facilitated action-planning

Further workshops are planned March–July 2024 and will continue to experiment with such methods to enable people to collaboratively explore these topics, community action and social change. Some deliberative methods may be used.

Participants in the first workshop (December 2023) reported it as 'thought-provoking', 'moving', 'stimulating' 'informative' and 'essential'. The use of short expert videos to introduce key Lancet Commission concepts was effective and elicited active discussion.

Participants' responses and creative outputs demonstrated that they had understood concepts including social determinants and dying as a relational and spiritual process, and had actively engaged in consideration of what could be different and how change might be achieved. Several expressed desire for further workshops to learn more and enable deeper exploration and to be involved in place-based change.

Creative and participatory methods are effective in communicating key concepts from the Lancet Commission on the Value of Death to community participants who lack prior knowledge of these issues. Community workshops are an effective method of engagement, and have potential to catalyse involvement in community action and system change to implement the Lancet Commission ideas.

ID: 381

Abstract Type: Poster

Topics: Social and structural determinants of death dying and grieving, Death and grief literacy

Keywords: bereavement, grief, systematic review

Experiencing bereavement: Preminilary results from an umbrella review

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Background: Experiencing grief is often a difficult ordeal for loved ones, who must rebuild their world and make new sense of life without the other (Neimeyer et al., 2010). The so-called "normal" grief experience is usually made up of emotional, cognitive, behavioral, and physical reactions (e.g., sadness, confusion, sleep disturbances, Worden, 2018) likely to occur following a significant loss.

Objectives: This study aims at systematically and exhaustively identifying the factors associated with coping strategies mobilized when experiencing the loss of a loved one.

Design: An overview of reviews (Gates et al., 2022) has been conducted to describe the various factors playing a role in individuals' coping with bereavement.

Methods: With a literature search supervised by a specialized librarian in several databases (e.g., PsycInfo, Medline, CINHAL) with appropriate keywords, 1299 potentially interesting studies have been identified (after duplicates have been removed). The selection of pertinent studies was conducted following two phases. In the first phase, two research assistants have independently screened titles and abstracts in order to include systematic reviews or mela-analysis describing factors associated to bereaved adults' experience published in English, French or German. In the second phase, the entire articles were read entirely by the same research assistants who applied the same inclusion and exclusion criteria. During the two phases, an interjudge agreement was calcuted and conflicts regarding studies inclusion were resolved in the presence of a third person. The whole process has been supported by the use of Covidence software and followed the PRISMA guidelines for overviews of reviews.

Results: Article selection is still ongoing at the time of the abstract submission, but this paper will present factors associated to bereaved adults' experience inspired by two theoretical framewroks: integrative approach developed by Cummings (2000) and the bioecological approach (Bronfenbrenner, 2005). The strenghts of those two approaches will allow us to describe both individual characteristics of bereaved people and sociocultural and environental contexts in which their experience takes place in a dynamic and integrated pespective.

Conclusion: Recommendations towards grief acknowledgement and prevention will be discussed as well as suggestions for further research.

ID: 382

Abstract Type: Poster

Topics: Networks and compassionate communities, Educational approaches

Keywords: Compassionate city, narrative medicine, palliative care

A model of narrative medicine in palliative care: how to use it to create a compassionate city

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Il Mosaico Servizi ETS

Introduction: The municipal administration, the associations present in the area that deal with chronic conditions, palliative care, disabilities, cultural projects, and education have supported the creation of a compassionate city that uses a model of narrative medicine, unique on an international scale, built on the philosophy of palliative care, but applicable to citizenship.

Goals: Building a compassionate city that uses narrative medicine as a structured model and improves awareness and knowledge of issues related to death, the end of life, care, fragility, enhancing the dignity of the person.

Design: The process of building the compassionate city, using a narrative medicine model for palliative care, began on February 1, 2024.

The first year will be dedicated to the following activities: the construction of the first nucleus of the compassionate city network through dissemination, training and information events with narrative methods; practical activity linked to the application of narrative medicine to improve people's quality of life; the creation of a formal document of the birth of the compassionate city and becoming part of the network of compassionate cities.

Methods: The program began with meetings between the municipality and the associations that participated; data on the use of narrative medicine in palliative care on people in hospice and followed at home in the year 2023 were presented; the values and objectives to be achieved have been defined; the concrete actions to be implemented have been identified

Results: The results that we want to achieve by February 1, 2025, are the following: Establish the first compassionate city that uses a narrative medicine model in palliative care; Extend the use of the narrative medicine model for palliative care to citizens; Administer, during narrative medicine activities, a questionnaire on how people feel supported by the community in which they live; Work to implement the Compassionate City in the years following the first

Conclusions: What made the process of building a compassionate city in our territory possible was the recognition of the importance of compassionate cities and narrative medicine in palliative care. Narrative medicine creates a bridge between people and institutions

People, including professionals, through their narratives, become active protagonists of the treatment process and feel free to talk about death, illness, fragility.

ID: 383

Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: Charter for the Care of the critically Ill and the Dying in Germany, Key Principle 1 of the Charter, a community-oriented (re)care culture, recommendations for action, social responsibility

Implementation of the Charter for the Care of the critically Ill and the Dying in Germany: Caring Communities - a joint task of politics, society and the hospice and palliative movement

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The Charter process from 2008 to 2016 significantly advanced the further development of hospice and palliative care in Germany on the basis of the 5 Charter key principles. The participation of over 50 institutions and organizations relevant to society and health policy in the consensus process underlines the importance of the goals of the Charter and the recommendations for action adopted by consensus. In particular, Key Principle 1 of the Charter emphasizes social responsibility and the necessary solidarity of fellow human beings when accompanying the dying. On this basis, the aim is to spread the topics of dying, death and mourning across society and thus (re) integrate them into the context of people's lives in Germany.

The aim of the further implementation of the charter is therefore to promote the development of caring communities (this also includes compassionate communities) in the spirit of the Charter for the Care of the critically Ill and the Dying in Germany in order to promote the (further) development of what is, above all, an institution-and professional-centered care at the end of life to a community-oriented (re)care culture in Germany, to strengthen citizens in dealing with the topics of dying, death and grief and to promote their skills.

Based on a qualitative nationwide inventory of the ongoing and completed (pilot) projects, two expert groups will be set up to support the development of sustainable caring community structures in Germany. One group is developing a workshop concept to support initiatives in establishing and expanding network structures around the topics of dying, death and grief. The other group develops recommendations for action in order to provide information on the launch and further procedure of corresponding initiatives.

Caring communities in the sense of the charter arise where professional actors in hospice and palliative care work together with civil society, private sector and political actors and work together to ensure the conditions for a dignified death for all local citizens and mutual care. The charter process can be linked here. The Charter Round Table has established itself as a suitable platform for joint work.

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ID: 384

Abstract Type: Oral presentation

Topics: Networks and compassionate communities

Keywords: community based participatory action research, public health palliative care, compassionate communities

Healthy End of Life Project (HELP) Ottawa: Circling back and moving forward

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Healthy End of Life Project (HELP) Ottawa, a community-based, participatory action research project which served as a pilot for a Canadian version of a similar research endeavor at LaTrobe University in Australia (Grindrod & Rumbold, 2016, 2018). Aligned with the work of Dr. Allan Kellehear (Kellehear, 2005, 2013, 2020, 2022) and the international Compassionate Communities movement, HELP Ottawa was funded by the Mach-Gaensslen Foundation of Canada, a private foundation, and sponsored by Compassionate Ottawa (a non-profit organization),and hosted at Carleton University.

Over the course of the project (2019-2022), HELP Ottawa worked at four sites, Christ Church Bells Corners, Orleans United Church, and Centretown and South-East Ottawa Community Health Centre, conducting baseline research, building capacity in research and community development, and developing, implementing and evaluating project initiatives based on the research findings. Over forty initiatives were implemented across the four sites, and eight multimedia toolkits have been created, to support other sites in building their own site-specific initiatives.

Building on the momentum established by HELP Ottawa, Tri-Council funding was received to support toolkit translation, knowledge mobilization, knowledge translation and capacity building through four community-site forums, and a community-wide Summit. The four forums will be tailored to each of the host sites and will include interactive presentations, experiential learning activities, and future planning. The Summit will engage a broader audience, including decision makers, to establish an Action Plan with the goal of building more compassionate responses to death, dying, grief, and loss in Ottawa. Each of the forums and the Summit will be open to the public and extend the knowledge mobilization beyond the community.

Engaging with over 200 participants, from community members, site facilitators, site leaders, health and social service providers, graduate students, government representatives, and policy makers through four forums and a final Summit. Further, we expect a wider audience will engage with the translated toolkits online. Our hope is to empower communities to be part of end-of-life care.