

Programme Abstracts of the 3rd International Seminar - A Human Rights based approach to Palliative Care: Towards Solutions for Public Health Palliative Care

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ORAL ABSTRACTS

Abstract ID: 1

Developing an evidence and theory based multimodal integrative intervention for the management of renal cachexia: a theory of change

Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Many health research advisory bodies have suggested that it is best practice to report on the Theory of Change (ToC) prior to piloting and evaluating an intervention to ensure the context and the effective elements of the intervention are understood. However, there are no previous ToC studies in relation to renal cachexia.

Objectives: The aim of this study was use ToC to develop a theoretical framework for a multimodal, integrative, exercise, anti-inflammatory and dietary counselling (MMIEAD) for patients with renal cachexia, to better understand the causal pathways, anticipated outcomes and most suitable evaluation methods.

Design: We used a Theory of Change (ToC) approach to guide six steps. Step 1 included

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inputs from a key stakeholder workshop, step 2 included the findings of our mixed-methods study and step 3 included the results from our systematic literature review. In step 4, we used wider research to identify the underlying causal pathways for renal cachexia. In steps 5 and 6 we developed and refined the ToC map in consultation with key stakeholders to illustrate how the intervention components of MMIEAD interact to achieve the intended long-term outcomes and anticipated impact.

Results: The ToC approach to this study provided a theoretical framework which allowed the context and effective elements of an intervention for renal cachexia patients to be better understood. We were able to develop a ToC map which not only allowed the design of a multi-modal intervention, but also delineation of the ‘causal pathway’, ‘ceiling of accountability’, ‘preconditions’ and identification of the ‘ultimate impact’ of the intervention (improved quality of life, optimal symptom management and reduced premature mortality). The ToC map will be used to form the basis of an evaluative cluster randomised controlled trial.

Conclusion: There have not been any previous studies that have used a ToC approach to develop an integrated multi-modal intervention for renal cachexia patients. Our ToC map will provide an evidence base for such integrated interventions aimed at improving quality of life, optimising symptom management and reducing premature mortality in patients with renal cachexia.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 19

Palliative care education and training interventions for healthcare professionals caring for people with dementia: A scoping review

Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Dementia is a progressive, incurable life-limiting illness. Proactive palliative care, delivered by multidisciplinary healthcare professionals (HCPs), may offer significant benefits to this vulnerable population. However, there is a paucity of evidence as to what constitutes effective education for HCP’s working in dementia palliative care.

Objectives: The aim of this scoping review was to explore the effectiveness of education and training interventions for multidisciplinary HCPs in dementia palliative care.

Method: The Joanna Briggs Institute (JBI) methodology was adopted for this study. Studies exploring palliative care educational interventions that targeted HCPs caring for patients with dementia were included. Study designs included quantitative, qualitative, and mixed method studies. The following databases were searched: CINAHL, ERIC, Medline, SocIndex, PsycINFO. The Kirkpatrick’s four level training model was used to examine the level at which interventions were evaluated.

Results: Seventeen articles met the inclusion criteria. The most common setting for delivery of palliative care education and training was in nursing homes. Nurses were the most represented participants, among HCPs who undertook training. The main learning outcomes evaluated were knowledge, communication skills, attitudes, content of the educational intervention and confidence. Most studies achieved Kirkpatrick Level 2, which evaluated learning. Multimodal approaches appeared to enhance learning via active participation of HCPs and direct patient involvement. However, not all studies detailed their interventions and there was significant heterogeneity in the design and evaluation of the study interventions included in this review.

Conclusion: Our findings highlight that there is a limited number of educational interventional studies undertaken to date for HCPs in the area of dementia palliative care. There was over representation of nurses and under representation of medical doctors/ allied health care professions. Consequently, there is a need to develop tailored educational interventional programmes

for HCPs, who provide end of life care to people with dementia.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 22

How willing are people to help their neighbours in need of support? A cross-sectional survey among the general public

Topics: Community based approaches to palliative care

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Background: People's social connections are increasingly recognised in supporting people with care needs. Health promoting initiatives in palliative care which involve people's social connections report positive outcomes but do not provide insight into how willing people actually are to support others within their proximity.

Objectives: We explore how willing people are to help their neighbours in need of support, and if there is a difference in their willingness depending on the type of support. We assess the correlation between different characteristics and experiences on people's willingness.

Design: Cross-sectional survey of the general public.

Method: We sent 4,400 questionnaires to a sample of people aged 16 and over in four municipalities in Flanders, Belgium.

Results: 2008 (45.6%) questionnaires were filled out. The type of support people were most willing to provide was going to the shop. People who believed they would receive support when in need were more willing to support their neighbours. Having a family care experience and having volunteered around serious illness or dying were associated with higher willingness.

Conclusion: People are generally willing to help their neighbours in need of support. This may be explained by our consideration of low-threshold, practical and emotional types of support. There is a potentially large informal support network available to individuals with support needs. Our research affirms the potential that lies in the public health strategy of strengthening and extending people's naturally occurring social networks. Policy interventions that focus on training potential carers and propose supportive options such as allowing carers to take a day off work, could effectively mitigate the progressive decline in available care providers.

Trial Registration (if applicable)

N/A

Funding Source

This research is part of the programme 'CAPACITY: Flanders Programme to Develop Capacity in Palliative Care Across Society', a collaboration between the Vrije Universiteit Brussel, Ghent University and the Catholic University Leuven, Belgium. This study is supported by a grant from the Research Foundation – Flanders, file number S002219N.

Conflict of Interest

None

Abstract ID: 27

Exploring Energy Hardship in Palliative Care at Home: The Nurse Perspective

Topic: The rights of patients and family carers

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Background: People with a life-limiting cancer diagnosis are more vulnerable to the cold but may struggle to afford to heat their homes. There appears to be little consideration of the needs of this energy hardship vulnerable group by energy companies, regulators or government policy.

Objectives: This study aims to address the evidence gap on energy hardship among people with a life limiting cancer diagnosis.

Design: The study uses a cross-sectional mixed methods design to get the perspectives of multiple stakeholders including patients/ families, nurses and energy providers/ regulator.

Method: Marie Curie UK undertook a similar study with palliative home care nurses previously, and permission was received to adapt their tool. Data from 44 questionnaires have been analysed to date using SPSS v.25 and thematic analysis.

Results: The findings indicate that 45% (n=20) of the homes where the nurses provide care do not have a central heating system. Instances of patients having to do without heating were reported by 32% (n=14) of the respondents. Draughts (92%), condensation (68%), damp (63%) and mould (58%) were evident in many homes. Evidence of financial struggles were reported by 19 (43%) respondents, and 13 (30%) recorded patients or their families initiating a conversation around energy hardship. Nurses believed that fuel poverty negatively impacted their patient's physical (n=14; 47%) and mental (n=18; 60%) health. Respondents described families being concerned of electricity costs while focusing on providing all they could for their loved ones requiring palliative care.

Conclusion: These preliminary findings suggest that energy hardship and the standard of housing is adversely affecting patients receiving palliative care at home and is a cause of concern to family members. It is hoped that recommendations from this study can be used by advocacy agents to promote more equitable policy decisions.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 28

The recognition, assessment & perceptions of total pain in people with profound intellectual disabilities - A mixed methods systematic review

Topic: Palliative care and underserved populations

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Background: People with profound intellectual disabilities (PID) are an extremely vulnerable population who are living longer with complex co-morbidities. Total pain recognises the multi-faceted, subjective nature of pain which includes the physical, psychological, emotional, social and spiritual.

Objectives: This review aims to synthesise current research in the area of total pain recognition, assessment and perceptions in people with PID in order to gain an understanding of current practices. It endeavours to highlight areas for future research in the improvement of care in this area.

Design: This is a mixed methods systematic review.

Method: Five databases were searched (Cinahl, PsycInfo, Scopus, Medline, Web of Science) and the studies retrieved were reported via the PRISMA guidelines. The MMAT (Mixed Methods Appraisal Tool) was utilised for quality appraisal. Data synthesis was completed with a convergent qualitative design and the results are presented through themes.

Results: Four themes were generated from the data of sixteen studies, Absent voices; Reductionist assessment; Pain intensity; and Valuing expertise. Physical pain was the only form of pain addressed in the included studies. Pain tools attempt to create methods of addressing communication challenges but due to individual methods of communication, these are not appropriate for all of this population. There is no explanation of when tools should be used in practice and pain intensity is mostly not addressed. The vast depth of knowledge that different forms of carers have is not interconnected in the research.

Conclusion: This review has explored a complex phenomenon and has created directions for future research in order to improve pain practices for this population. It is clear that there is a need for less reductionist and more holistic assessments for this population, including total pain and all available assessment methods. Pain intensity must be addressed. The sharing of knowledge is essential for best practice.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 31**Mixed-methods evaluation of a face-to-face educational intervention for health and social care professionals to deliver family-centred cancer supportive care when a parent with dependent children is at end of life**

Topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: Health and social care professionals (professionals) often highlight a lack of knowledge, skills and confidence toward supporting parents at end of life (EoL) with cancer regarding their children (<18 years).

Objectives: To determine the effects of a face-to-face educational intervention on professionals self-efficacy to deliver family-centred cancer care when a parent with dependent children is at EoL.

Design: Mixed-methods study.

Method: An evidence-based 2-hour face-to-face educational intervention was developed, which included a bereaved parent's lived experience. This intervention was delivered interdisciplinary, mainly at oncology settings (n = 14), facilitated by two expert academic nurses to 347 professionals, between September 2021 and September 2023. Quantitative surveys were completed immediately before and after the intervention by 216 professionals using a modified validated self-efficacy scale and single-item questions evaluating perceived usefulness and relevance. At ≥ 3 -months post-intervention, qualitative interviews (n = 14) explored professionals' perceptions if and how the intervention impacted practice; analysed using reflexive thematic analysis.

Results: Quantitative findings highlighted a statistically significant improvement in self-efficacy post-educational intervention ($p < 0.001$). Qualitative data highlighted professionals were more confident in taking an active role in initiating pre-bereavement conversations with parents about

their children. This included reassuring parents of the importance of telling the children about the poor prognosis, and guidance on how best to do this. Key components from the educational intervention positively shaping clinical practice, included the bereaved parent's lived experience, the communication framework and videos emulating good practice. Findings are discussed under two themes: (1) the power of art, science and lived experience to education provision, and (2) promoting family-centred cancer care in practice.

Conclusion: Professionals are ideally placed to support parents as they prepare children for the death of a parent. Evidence- and theory-driven education appeared to positively impact professionals' provision of family-centred cancer care in practice. A more sustainable delivery model of this educational intervention is required.

Trial Registration (if applicable)

N/A

Source of funding

None

Conflict of Interest

None

Abstract ID: 42**Pride In Death: Hosting an LGBTQIA+ focused death cafe**

Topic: Palliative care and underserved populations

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Background: Thinking, talking, and recording your choices and values for your care at end of life is a vital part of advance care planning.

However, fear that asserting their identity will lead to discrimination or neglect creates an additional barrier for LGBTQIA+ People.

Objectives: We held tender conversations with the LGBTQIA+ community to understand and explore what their key issues are in relation to death and dying, and what really matters to them in planning ahead for their end of life care.

Design: Followed loose structure of Death Café with Advanced Care Planning as main conversation driver.

Results:

1. LGBTQIA+ people suffer from ambiguous and complicated grief due to a variety of issues specific to being LGBTQIA+ and the creation of specific Bereavement Support Groups is essential.
2. The desire for younger and older LGBTQIA+ people to connect with one another is reciprocal, but there are few (if any) places to connect across generations. Creating safe spaces for intergenerational networks to be developed is important.
3. Need for LGBTQIA+ End of Life Reference Group that collaborates with people writing and designing health resources for end of life care.
4. Creative engagement and communication outside religious rituals is required to ensure LGBTQIA+ People's identities as well as their chosen families, are respected and acknowledged until the very end.
5. LGBTQIA+ Nursing Homes. Fear of discrimination and having to go 'back in the closet' urges the need for a LGBTQIA+ only nursing home.
6. Host more LGBTQIA+ Death Cafes.

Conclusion: Palliative Care services are supposed to be person centred but if you do not truly understand the person, services will always be lacking. By having honest conversations with individuals from different communities, we gain insight and trust that will enable services to be designed with the true individual at heart.

Trial Registration (if applicable)

N/A

Source of funding

None

Conflict of Interest

None

Abstract ID: 45

Cost consequences of unscheduled emergency admissions in cancer patients in the last year of life

Seminar topic: Public Health Palliative Care

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Background: Cancer is a leading cause of death. People with palliative care needs are high users of unscheduled care in the last months of life.

Objectives: To examine utilisation of unscheduled emergency end-of-life healthcare and estimate expenditure. To explore care patterns and quantify the likely benefits from service reconfigurations which may influence rates of hospital admission and deaths

Design: Using prevalence-based retrospective data from the Northern Ireland General Registrar's Office linked by cancer diagnosis to Patient Administration episode data for unscheduled-emergency-care (1st January 2014 to 31st December 2015), we estimate unscheduled-emergency-care costs in the last year of life. We model the effects of reductions in length-of-stay for cancer patients and by linear regression examine patient characteristics affecting length of stay.

Results: 3134 cancer patients used 60,746 days of unscheduled emergency care (average 19.5 days). Of these, 48.9% had ≥ 1 admission during their last 28 days of life. The total estimated cost was £28,684,261, averaging £9,200 per person.

Lung cancer patients had the highest proportion of admissions (23.2%, mean length-of-stay = 17.9 days, mean cost=£7,224). The highest service use and total cost was in those diagnosed at Stage IV (38.4%), which required 22,099 days of care, costing £9,629,014. Palliative care support, identified in 25.5% of patients, contributed £1,322,328. A 3-day reduction in mean length-of-stay with a 10% reduction in admissions, could reduce costs by £7.37million. Regression analyses explained 41% of length-of-stay variability.

Conclusion: The cost burden from unscheduled care use in the last year of life of cancer patients is significant. As such the opportunities for service reconfiguration to influence high-costing users would in the first instance prioritise lung and colorectal cancers as these groups offer the greatest potential to influence outcomes.

Trial Registration (if applicable)

N/A

Funding Source

This research was conducted using data from the Northern Ireland Cancer Registry (NICR) which is funded by the Public Health Agency of NI (VC, AG). The primary author (EMF) was funded by grants from Cancer Focus Northern Ireland and Health Data Research UK. VC was funded through the Macmillan-NI Cancer Registry Partnership (2016). ML acknowledges grant funding from his roles as Associate Director of Health Data Research Wales-Northern Ireland and Scientific Director for DATA-CAN, The Health Data Research Hub for Cancer. The interpretation and conclusions of the data are the sole responsibility of the authors.

Conflict of Interest

ML declares honoraria from Bayer, Carnall Farrar, EMD Serono, Novartis, Pfizer, and Roche unrelated to this work.

Abstract ID: 51**Empathy in every action - mastering post death care and empowering staff with a comprehensive care after death check list -**

Seminar topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Providing comprehensive and compassionate care after death is essential for ensuring dignity and respect for patients and supporting their loved ones. However lack of standardised protocols and guidelines leads to variations in post death practices. This study was to develop a care after death checklist which encapsulated the necessary paperwork per patient in one easy to use and follow booklet.

Objectives: To design and implement a simple but comprehensive checklist that covers aspects of the dying phase, and following death including legal requirements, patient body handling, documentation and support for bereaved families.

Design: Comprehensive literature review and benchmarking, expert consultations, and input

from healthcare workers in the hospital especially those whose expertise lay in end of life care. The checklist was developed on existing guidelines with input from key stakeholders. Design included iterative revisions and pilot testing to ensure feasibility in real world situations.

Method: The research team conducted a literature review to identify key components of care after death. Expert consultations to gather insights and recommendations from professionals in various disciplines, including palliative care, nursing, anatomical technicians, funeral and legal services.

Results: Now a staple tool in the hospital. The pilot illustrated improvements in after death care with staff reporting they feel more competent providing care to patients. The checklist is used for training new staff and ensures the holistic care throughout. Fewer exceptions are reported, and families are better supported with better signposting and prompts from the checklist at many points along their journey.

Conclusion: We have developed a standardised, comprehensive and holistic approach to patient and family care promoting dignified practices across healthcare settings. The checklist facilitates effective communication enhances documentation accuracy. The checklist is now embedded in the model 4 hospital and is being introduced to model 2's to ensure continuation of care following death.

Trial Registration (if applicable)

N/A

Source of funding

None

Conflict of Interest

None

Abstract ID: 52**Psychometric validation of the Death Literacy Index and benchmarking of levels of death literacy in the UK**

Seminar topic: Death and grief literacy

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Background: The Death Literacy Index (DLI) is the first measure worldwide aiming to understand and evaluate levels of death literacy within a community. Developed in Australia, the measure is increasingly being validated internationally and used with the potential to help both inform the development of and evaluate public health interventions.

Objectives: The current study aimed to provide the first psychometric validation of the DLI in the United Kingdom, alongside population-level benchmarks of death literacy constructs.

Design: A psychometric validation study using a large online panel (n = 399 participants), representative of the UK population by age, gender and ethnicity.

Method: Confirmatory factor analysis was undertaken to test the factor structure of the 29-item DLI, alongside assessment of internal consistency of subscales, and assessment of convergent and discriminant validity with theoretically related/unrelated constructs. Descriptive statistics were used to present population-level benchmarks for the DLI and subscales.

Results: The factor structure of the DLI was supported, with the best fitting model including one substituted item for UK respondents. There was high internal consistency across subscales. Convergent validity was evidenced in relation to objective knowledge of the death system, death competency and actions relating to death and dying in the community. Discriminant validity was evidenced in relation to loneliness. Known-groups validity was evidenced with respondents with professional or lived experience of end-of-life care reporting higher levels of death literacy. Population-level benchmarks were near the mid-point of the DLI total and subscales.

Conclusion: The Death Literacy Index is a psychometrically robust tool to use in the UK to assess levels of death literacy. The findings indicate that the death literacy of the UK public could be strengthened, particularly around factual knowledge of the death system and accessing help when needed for themselves or others.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 56

Building death and grief literacy in a coastal town: Good Grief Weston festival

Seminar topic: Death and grief literacy

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Background: Festivals play an important role in improving death and grief literacy, enabling members of the public to engage with these often-sensitive topics. Good Grief Weston festival was co-designed and delivered with the community, and held in person over 8 days in May 2023 in a coastal town with high levels of socio-economic disadvantage but rich community assets.

Objectives: To evaluate the reach and impact of Good Grief Weston and gather data to inform future festivals.

Design and/or Method: Mixed methods evaluation (survey and focus groups).

Online and paper surveys assessing participants' characteristics and experiences were administered during and after the festival. Survey participants who indicated their willingness to participate were invited to attend a focus group. Focus groups were recorded, transcribed and analysed using thematic analysis. Data were collected by trained community co-researchers.

Results: Approximately 3000 people attended the festival. Of 205 completed surveys, 62% were from women, age range ≤ 15 to ≥ 75 years; 88% identified as white; 14.1% deaf, disabled/with a chronic condition; 18% neurodivergent; 9.3% gay, bisexual or queer. Festival participants were entertained (73.2%), inspired (70.2%), felt part of a like-minded community (52.7%), talked to someone new (48.3%), learnt about grief/bereavement (35.1%), shared or expressed experiences (29.8%) and found out about local support (20.5%). 67.8% reported that through attending they felt more confident talking about grief. Mean

experience rating was 4.8 (SD 0.47) (possible range 1 = poor to 5 = excellent). In free-text comments most participants expressed appreciation for the festival and described the benefits of attending. Two focus groups were conducted (n = 8 participants, all women), lasting c.1.5 hours. Focus groups added rich descriptions of the festival's value, and data to inform the next festival.

Conclusion: Findings suggest festivals of this nature can play a central role within a public health approach.

Trial Registration (if applicable)

N/A

Funding Source

Arts and Humanities Research Council

Conflict of Interest

None

Abstract ID: 58

The Financial Impact of Bereavement in Ireland

Seminar topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: The right to an adequate standard of living is enshrined in the UN Declaration of Human Rights, including security in widowhood or other circumstances outside of one's control (Article 25).

The costs of bereavement are multidimensional, multifactorial and intertwined. For some the impacts are temporary, for others they are significant impacting on their ability and capacity to continue with daily life.

This is the first study in Ireland examining the financial impact of bereavement, from funeral costs to longer-term impacts on health, employment and a person's wellbeing.

Objectives:

- Assess knowledge, attitudes, behaviour and experience of the Irish public around economic aspects of bereavement

- Describe the economic impact of bereavement on a variety of cohorts, including those who have been bereaved and those providing services to support the bereaved
- Identify policy and practice implications for supporting people who are bereaved

Design and/or Method: A mixed methods design was used, incorporating a national survey, semi-structured interviews and focus groups.

A survey of a representative sample of 1,000 adults in Ireland was used to assess knowledge, attitudes, behaviour and experience of the financial impact of bereavement. Interviews were conducted with bereaved people (n = 7) and focus group discussions held with professionals and service providers (n = 24).

Results: Findings demonstrate that the financial impacts of bereavement are much broader than immediate costs associated with a funeral. These impacts include changes in household income, negative effects on a person's health and employment circumstance. There is a clear lack of knowledge and awareness about state supports among bereaved people and the wider public.

Conclusion: The study highlights the importance of ongoing supports for people who are bereaved: information on payments and resources; changes in employment laws; and access to services to ensure wellbeing is supported throughout the grieving process.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 60

Compassionate Communities: How do we know we are making a difference?

Seminar topic: Compassionate Communities

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Background: Public health palliative care aims to unite health-promoting social activities across complex community-based support networks.

Improvement outcomes can be unexpected and unpredictable. Identifying robust evidence of benefit using reductionist research models is challenging.

Objectives: To explore the methodological contribution of a complexity-informed approach to evaluating community-based public health palliative care improvement initiatives.

Design and/or Method: A mixed-methods case study assessing the social learning capability and impact of a citizen-led community of practice [CoP] using a contribution analysis framework.

Using community-based participatory research principles, citizens were invited to join a CoP, with knowledge mobilisation support from an academic researcher. The CoP used an asset-based approach to activate participatory action learning through enacting elements of the Compassionate Communities Charter.

CoP members first performed a collaborative context analysis to identify the risks and assumptions surrounding the planned community organising intervention co-led by externally commissioned outcome evaluation specialists.

The context analysis output formed the basis of a co-designed outcome map using programme theory that considered six themes: i) co-produced activities that aligned with the Charter, ii) tracking stakeholder networks involved, iii) how CoP members responded to being involved, iv) what knowledge and skills they gained, v) what changes occurred to their behaviour, and vi) what difference they believed the CoP had instigated overall.

Results: CoP members included representatives from local charities, schools, volunteer groups, funeral homes, faith groups, artists, and the local town and county councils. Collectively, the CoP aligned activities with 7/13 social changes outlined in the Charter. The most significant change, directly attributable to the CoP, enabled someone to die at home according to their wishes, rectifying a failed hospital discharge.

Conclusion: The complexity-informed contribution analysis framework enabled the community-based participatory research process to be authentically co-produced throughout. It provides a promising alternative to positivist traditions.

Trial Registration (if applicable)

N/A

Funding Source

Local NHS Clinical Commissioning Group

Conflict of Interest

None

Abstract ID: 63

Developing Compassionate Workplaces to protect employees' health and wellbeing: presentation of the international EU-CoWork project

Seminar topic: Compassionate Communities

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Background: A significant proportion of employees will experience serious illness, caregiving, death and loss (end-of-life (EoL) experiences) during their professional life. These affect employees and their colleagues' health and wellbeing as well as workplace productivity and safety. The twin (digital and green) transitions have influenced job demands and resources of jobs and work environments such that employees can feel less or not supported when coping with EoL experiences.

Objectives: We developed the EU-CoWork project to 1) understand the influence of changing workplace organization due to the twin transitions on wellbeing, performance, job quality, and work culture for employees confronted with EoL experiences and their colleagues; 2) develop and evaluate tailored Compassionate Workplaces Programs (CWPs) to support employee health and wellbeing in the work environment, across

different national and occupational contexts in Europe.

Design and/or Method: The project entails a 4-country (Belgium, Sweden, Austria, Greece) cross-national mixed-methods intervention study with an embedded process and impact evaluation. It applies an international co-creative and developmental evaluation of tailored CWP, and mixed-methods process and impact evaluation combining a timed series of quantitative cross-sectional panel surveys, qualitative interviews and fieldwork, and policy document analysis. Tailored CWPs will be developed in 12 digitalized and/or green European workplaces.

Results (Anticipated results): EU-CoWork will generate findings about workplace compassion, mental and physical health and wellbeing of European employees; the relationships between workplace characteristics, workplace compassion, and health and wellbeing of employees confronted with EoL experiences; between employees' EoL experiences, company responses to these, and company and employee performance; and the variability in European workplace policies addressing such risk factors.

Conclusion: EU-CoWork will offer building blocks for workplaces to ensure adequate and tailored support and policy to counter-balance experiences that may exacerbate the risk for adverse mental health and wellbeing outcomes for employees, and insights regarding CWP-related productivity gains and cost-effectiveness.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 64

Looking forward: exploring the priorities for public health palliative care research in Europe in the coming decade

Seminar topic: Public Health Palliative Care

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Background: Recent years have seen growing international recognition of public health perspectives in palliative care (PC) research, resulting in a range of new research approaches. However, there is currently no consensus on a research agenda for Public Health Palliative Care (PHPC).

Objectives: Set a consensus-based PHPC research agenda for Europe for the next 10 years, to complement clinical and wider PC agendas.

Design and/or Method: A European, mixed method, online Delphi study, with a digital survey questionnaire.

Snowball sampling was used to recruit people with relevant expertise in PHPC from an initial list of 80 experts from 16 countries. Experts were asked to rank a list of 62 potential research priorities (derived from earlier Open Meeting discussions) on 5-point Likert scales for appropriateness, relevance, feasibility and impact. Research Priority Scores (RPS) were calculated as mean item scores across criteria and raters. Average Expert Agreement (AEA) was calculated as mean proportion of raters who scored the mode result on each criterion per item.

Results: Sixty-five responding experts prioritized research related to equity, access and power, integrated PC, care capacity, understanding death systems, outcomes and experiences, methodology, and unforeseen outcomes. Fifty items had high priority (RPS=3,6–5), and 1 with low priority (RPS < 2,5) was removed. Experts disagreed most about methodology and settings-based approaches. Thirty-seven items displayed $\geq 70\%$ agreement and 25 uncertainty (30% - 69%). Spider graphs revealed 89% of items scored highest on appropriateness, and 86% lowest on feasibility. Qualitative responses led to removal of 16 items (due to redundancy, vagueness or leading), addition of 3, and rephrasing of 24, resulting in a new list of 49 items.

Conclusion: Overall high scores may be due to item redundancy, vague formulation or skewing by high appropriateness scores. Preliminary results emphasize priority for equity and systems

approaches, but disagreement about popular ‘new public health’ approaches.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 65

Development of a Theory of Change for the evaluation of evidence-based, practice- and citizen-informed palliative care policy in Flanders

Seminar topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: The Flemish population is ageing and a sharp rise is expected in the need for palliative care (PC) and in mortality associated with severe disease-related suffering. Through a participatory process, Flanders is working on a vision and action plan to reform PC towards integrated care. The Department of Care brought together stakeholders in palliative care to help define the vision of the reform (Sep 2022 - Jun 2023).

Objectives: Develop a programme theory to evaluate the policy around the reform of PC towards integrated, targeted and quality care.

Design and/or Method: Developmental Evaluation, an iterative process in which stakeholders are consulted at set intervals and evaluation decisions are made as a function of development.

Through participatory observation at stakeholder meetings, and document analysis, we establish a Theory of Change (ToC) that tells us which actions will lead to which outcomes, why, and

how to monitor the intended changes to evaluate policy.

Results: First, the intended impacts were defined. The finality of the reform is that everyone in Flanders who needs it receives integrated, goal-oriented, and person-centred PC and an important means to that end is to integrate generalist PC into primary care via care teams around the person with serious illness and their relatives. Through ‘backcasting’, the necessary outcomes and activities for the intended impact were determined. These focus on three pillars: 1) the training of all primary care providers in PC by implementing basic, specialist, and ongoing training, 2) care provision and coordination through interdisciplinary care teams at the primary care level, and 3) public awareness about end-of-life and PC through public campaigns.

Conclusion: Drafting a ToC is an intensive process of tuning and adjusting, but crucial to arrive at a vision supported by stakeholders. Clear mandates, responsibilities and timeline for the transition are needed to give them perspective.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 66

Dying Well at Home; Planning for equity, choice and dignity in end-of -life care

Topic: The rights of patients and family carers

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Background: Research consistently demonstrates dying at home as the preference for most people. However, providing equitable end-of-life care at home can be challenging. A ‘Dying Well at Home’ programme aims to support people to die well at home if this is their wish and it is possible.

Objectives: To understand the varied experience of dying at home in Ireland, specifically

1. What constitutes a good death?
2. What factors facilitate patients to have a good death at home in Ireland?
3. What factors prevent someone from dying at home in Ireland?
4. How has the Covid-19 pandemic affected end-of-life care at home in Ireland?

Design and/or Method: A qualitative design involved online focus group sessions with stakeholders (professional and unpaid) from various backgrounds.

Online focus group discussions were held with 49 participants from 15 organisations. Discussions were recorded with consent. Thematic analysis was used to code responses into common themes and subthemes.

Results: A good death was described as comfortable, calm, free from pain and suffering; honouring end-of-life wishes of the patient, allowing them to die with dignity.

Factors which facilitated good end-of-life care at home were families being informed; access to specialist palliative services; continuity and coordination of care across medical providers; timely access for pain management.

Barriers to dying well at home were lack of coordination between medical teams, incomplete information about end-of-life care, lack of 24-hour support, unequal access to palliative care services, under-resourced medical teams, and lack of integration with social services.

Conclusion: Inconsistencies in provision of end-of-life care were apparent. Financial, psychological, physical, emotional pressures placed on families, carers, healthcare professionals result from lack of resources and larger systemic failures. Care systems need to be mapped, how to access care should be transparent, inequity of services across regions must be addressed. Findings will shape the 'Dying Well at Home' programme.

Trial Registration (if applicable)

N/A

Funding Source

Pobal

Conflict of Interest

None

Abstract ID: 68

Role of caregiving burden and contact with palliative care in use of formal bereavement support: secondary analysis of a population-based study

Topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: Bereavement services have been underutilised in comparison to the prevalence of the high level of need for support. The reasons behind this are still unknown.

Objectives: To examine the influence of caregiving burden and involvement of palliative care (PC) on the utilization of formal bereavement support (BS) in family caregivers of persons who died of cancer.

Design and/or Method: Secondary analysis of the QUALYCARE study data, a mortality follow-back postal survey.

The population presented bereaved relatives of adults who died of cancer (London, UK) from four health districts in London who registered the death of an adult due between March 2009 and March 2010. We ran a multivariate logistic regression to determine the extent the independent variables explain the utilisation of BS.

Results: Out of 1516 eligible participants, 596 (39.3%) completed the survey, sometime between four to ten months after the loss. In a pool of 523 family members involved in caregiving (66% women, Mage=59; SD=14, 43% spouses/partners, 41% adult children), 149 utilized formal BS (73.8% women, Mage=60; SD=14, 55% spouse/partner, 36% adult children). Grief intensity (measured by the Texas Revised Inventory of Grief) was higher than the reported norms. Bivariate analysis confirmed the hypothesised associations, however, they were not retained in the multivariate model. Utilization of BS was associated with presence at the moment of death (Odds ratio 1.769, 95%CI=1.044–2.994) and grief intensity (1.036, 95%CI=1.015–1.058).

Conclusion: If grief intensity is a proxy of need for support, then BS is getting to those who need it. The role of presence at the moment of death should be explored further. To understand better the role of caregiving burden and PC in accessing BS we need to look beyond the rates of utilisation of support by asking how wanted, adequate and helpful was BS.

Trial Registration (if applicable)

N/A

Funding Source

Calouste Gulbenkian Foundation, Foundation for Science and Technology Portugal

Conflict of Interest

None

Abstract ID: 69

Brilliant palliative care: Partnering with culturally diverse communities using participatory visual methods

Seminar topic: Palliative care and underserved populations

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Background: Approximately 20% of the Northern Adelaide population are from non-English speaking backgrounds – this represents a larger community of culturally and linguistically diverse people when compared to the rest of South Australia. Palliative care benchmarking data show that people of diverse cultural backgrounds are not representative of the population. A report commissioned by Palliative Care Australia further highlights a range of barriers that hinder access to palliative care services for people of culturally diverse backgrounds. Despite the importance of culturally-appropriateness, palliative care does not always meet changing needs and preferences. Palliative care for these communities is often plagued by myriad barriers and issues.

Objectives: Rather than add to the discourse on all that is wrong with palliative care, this study

purposely aimed to establish what constitutes brilliant palliative care for these communities. Brilliant palliative care is understood to be that which exceeds expectation, bringing joy and delight to those who experience or witness it.

Design and/or Method: This qualitative study was underpinned by positive organisational scholarship and Merten's transformative research approach.

The study involved reflexive discussions with leaders of culturally and linguistically diverse communities. The focus of these discussions was video footage of palliative care in acute services, particularly that which clinicians, patients, and carers (who were not part of the aforesaid communities) deemed to be brilliant.

Results: Collectively, African (8), Syrian (3), and Nepalese (7) indicated that culturally brilliant palliative care involves: respect for cultural norms, while challenging taboos; the aptitude to step in, not back; as well as engagement with pre-existing compassionate communities.

Conclusion: Leveraging visual data from a previous study and working together with community leaders led to co-produced films to raise the profile of culturally brilliant palliative care. These were tailored for different audiences including communities themselves and disseminated via different avenues.

Trial Registration (if applicable)

N/A

Funding Source

None

Conflict of Interest

None

Abstract ID: 72

Using routine data to understand inequity in palliative, end-of-life and bereavement care: A cross-sector project in a coastal community

Seminar topic: Public Health Palliative Care

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Background: Palliative and end-of-life care (PEoLC) and bereavement support are less available to the most deprived communities in England, many of which are in coastal areas. Integrated Care Systems coordinate diverse community stakeholders with health and social care. They are mandated to tackle health inequities, however the extent to which existing data enables this is poorly understood.

Objectives:

- (1) Investigate inequities in PEoLC or bereavement support using existing data in a coastal region (North Somerset, England)
- (2) Use a collaborative approach to create a local digital dashboard on this topic.

Design and/or Method: Mapping and integration of local data sources and assets.

An epidemiologic approach investigated the impact of protected characteristics on PEoLC and bereavement support. Data resources included the Joint Strategic Needs Assessment, census data (2021), ONS death registrations, English indices of deprivation, Department of Work and Pension, school attendance and employment data, hospice data.

Results:

- (1) There were 11.1 deaths per 1,000 population (2019-2020), with a correlation between increasing deprivation and mortality (per 1,000, most deprived 15.2 deaths vs. least deprived 7.7 deaths), equating to a 7.8-year age gap for men between the least and most deprived quintiles (women 6.4 years). Routine health and social care data provided a limited understanding of access to and experience of PEoLC and bereavement services, primarily due to poor recording of recognised PEoLC need and little identification of bereavement. Other barriers included fragmented care home data and a lack of integrated hospice data.
- (2) An open-access dashboard was created, available on the Council website (n-somerset.gov.uk).

Conclusion: We successfully created a dashboard to engage and inform stakeholders. However, clear identification of PEoLC need or

bereaved individuals is lacking in routine data, as are routine indicators to capture key outcomes. The medical examiner role may represent an untapped opportunity to capture important data.

Trial Registration (if applicable)

N/A

Funding Source

Arts and Humanities Research Council/ UK Research and Innovation (UKRI)

Conflict of Interest

None

Abstract ID: 73

Caregiving experiences in the last year are associated with neighbourhood participation regarding serious illness, death and loss: A cross-sectional survey study

Topic: Compassionate Communities

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Background: Experience-based learning is promoted as a strategy for developing death literacy and stimulating neighbourhood participation regarding serious illness, death and loss.

Objectives: We aimed to examine how citizens' personal experiences with serious illness, caregiving, death and loss in the last year are associated with neighbourhood participation regarding serious illness, death, and loss.

Design and/or Method: We distributed a cross-sectional survey study in two geographically defined neighbourhoods in Flanders, Belgium, before the development of compassionate communities in these neighbourhoods.

We sent a questionnaire between February and April 2021 to a random sample of 2,324 citizens aged 18+ years. We performed linear regression analyses to study the associations between experiences with serious illness, death and loss in the last year, believed capacities, skills and self-efficacy developed such previous experiences and neighbourhood participation regarding serious illness, death and loss.

Results: The survey was completed by 714 citizens in the two neighbourhoods (response rate

31%), of which 72% had a personal experience with illness, death or loss in the past year. Having had a caregiving experience in the last year was associated with neighbourhood participation regarding serious illness, death and loss ($\beta=0.152$; $CI=0.480-1.545$); this association increased when adding believed capacity and skills developed from previous experiences to the analysis.

Conclusion: Our findings suggest that citizens who had a caregiving experience in the last year are more likely to participate in neighbourhood activities regarding serious illness, death and loss (e.g. volunteering, helping neighbours) and that they are more likely to participate if they believe they developed capacity and skills from their previous experiences. Former caregivers may be an interesting group to identify, as neighbourhood participation regarding these topics may provide them with a meaningful post-caregiving experience.

Trial Registration (if applicable)

N/A

Funding Source

Research Foundation Flanders, file number S002219N.

Conflict of Interest

None

Abstract ID: 82

Reflecting on Bereavement during Covid-19: using survey data from Ireland to examine public health implications

Topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: Covid-19 and restrictions impacted bereavement. Reference to a 'tsunami of grief' has not helped in understanding the diversity and nuance of bereavement. Some surveys^{1,2} describe elevated needs, others show adaptation in grief³. A public health model

emphasises risk factors, strengths & levels of support⁴.

Objectives: Describe the impact of bereavement during two years of Covid-19 restrictions.

Review bereavement Covid-19 with respect to a public health model

Design and/or Method: Cross-sectional national survey.

A survey of 38 questions including the Brief Grief Questionnaire⁵ to screen for Prolonged Grief Disorder (PGD) was disseminated using purposive, non-probability-based sampling. Descriptive and inferential statistics were generated. Open-ended data were analyzed thematically.⁶

Results: 2,259 responses were received; 1223 (68%) were bereaved of someone close during the pandemic, 478 experienced multiple losses. Deaths were due to Covid-19 (22%); cancer, (41%) circulatory system (22%). Only 24% were with the person when they died (267/1126), 93% believed their experience of death was negatively affected by Covid-19; 63% strongly agreed/agreed that their grief was made more difficult by Covid-19. Most attended the funeral (62%, 697/1116). Even with restrictions 82% (638/1114) said aspects of the funeral were comforting; 85% said people in the community found ways to honour the person who died; 53% (n=580) reported their family and friends found meaningful ways to support them in grief. Most had no PGD (59.6%); 14% indicated PGD and 26% were sub-threshold. 40% (n=396) reported not getting the support needed after the death due to restrictions, higher percentages who agreed/strongly agreed with the statement had indications of PGD, as well as those experiencing loss of a child or spouse.

Conclusion: Funeral rituals and community support were helpful. While smaller indications of PGD were found than in other Covid-19 research, inclusion of threshold scores increased levels of concern. Unmet bereavement support need exists, qualitative accounts of experiences help to understand these.

Trial Registration (if applicable)

N/A

Funding

Irish Hospice Foundation and Research Ethical approval from RCSI

Conflict of Interest

None

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Abstract ID: 104**Frequency and trends in deaths at nursing homes in older people: population-level study using death-certificate data in 18 countries**

Topic: Public Health Palliative Care

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Background: The ageing of societies has increased the importance of nursing homes as place of death.

Objectives: We aim to compare cross-nationally the frequency of nursing homes as place of death (PoD) and the trends over time between different age groups of people aged 70 or older across a 10-year period (2012–21).

Design: Population-level analysis of aggregate death certificate data.

Design and/or Method: We sought national PoD data from vital registries of 47 countries varied in UN Regions and were able to include 26, 18 with PoD categories that we identified as “nursing homes or similar” (NH; e.g., “nursing home”, “care home” or “nursing/long term care”). We described the percentage of NH deaths by age group (70–79y, 80–89y, ≥90y) and country, per cause of death [cancer – ICD-10 codes C0–C97 (except C91–95) and dementia – F01–03, G30, G31], and period (2012–13, . . . , 2020–21).

Results: We analysed 37.1 million deaths of people aged ≥70 (70–79y: 30.2%; 80–89y: 43.6%; ≥90y: 26.2%). NH deaths increased with age in every country (overall – 70–79y: 18.2%; 80–89y: 26.5%; ≥90y: 37.5%). For cancer deaths, this happened in every country (overall – 70–79y: 20.4%; 80–89y: 25.1%; ≥90y: 33.5%) and dementia in 12 countries (overall – 70–79y: 51.7%; 80–89y: 53.9%; ≥90y: 59.5%). There was no consistent time trend across countries in the percentage of NH deaths; most common was a constant increase until the pandemic and a reduction afterwards but only in 6 countries or less per age group.

Conclusion: Subject to the limits of comparability of PoD categories across countries, we observed that nursing homes are a relevant place of death in older people, especially for those above 90y and that the majority of deaths occurred there when cause was dementia. Countries should include nursing homes in their classification of PoD and allocate palliative care resources according to needs in this setting.

Trial Registration (if applicable)

N/A

Funding Source

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Conflict of Interest

None

POSTER ABSTRACTS

Abstract ID: 2

Exploring the lived experience of cachexia for individuals with end-stage kidney disease and the interrelated experience of their carers

Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Cachexia is an important consideration in the person-centred care that is needed in end-stage kidney disease (ESKD). However, given that clinical guidelines relating to cachexia in ESKD are largely absent, this is an unmet care need.

Objectives: To understand individuals' experiences of cachexia in ESKD and the interrelated impacts on carers in their lives to inform guidelines and future ESKD service planning.

Design: A purposive sampling strategy is being used to recruit individuals living with ESKD who have cachexia and their carers (n = 12) across two nephrology directorates, within two healthcare trusts in the United Kingdom. Interviews are audio-recorded, transcribed verbatim and analysed using interpretative phenomenological analysis. Ethical approval for this study was granted by the Office for Research Ethics Committees Northern Ireland (REC Reference: 22/NI/0107).

Results: Analysis has generated five preliminary themes: reduced appetite; reduced functionality;

weight loss interpreted as a bad sign; social impact of cachexia; tension over feeding. Data reflects the multidomain impact of cachexia on patients with ESKD, impacting on biological, psychological and social domains. Furthermore, analysis confirms that the impact of cachexia in ESKD affects not only patients but also their loved ones who care for them in the domiciliary setting.

Conclusion: These preliminary insights are a critical first step in the development of care that both recognises and responds to the needs of this population. The findings of this study will help healthcare providers understand the challenges that individuals with ESKD and their carers face in relation to cachexia and inform future clinical practice guidelines. Further research and supportive interventions which are co-designed to address the multifaceted impact of cachexia in ESKD are urgently required.

Trial Registration (if applicable)

N/A

Abstract ID: 3

Examining the acceptability and feasibility of the COMPASIONATES Mindful Resilience (CMR) programme in Adult Patients with Chronic kidney disease: The COSMIC Study findings

Topic: Compassionate Communities

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Background: People with advanced kidney disease face multiple challenges associated with the disease and renal replacement therapy such as increased anxiety and depression. The COSMIC study aimed to support a new service development project, in collaboration with Kidney Care UK, by implementing the Compassionate Mindful Resilience (CMR) programme, developed by MindfulnessUK, and explore its feasibility for patients with stage 4 or 5 kidney disease and kidney transplant recipients.

Objectives: N/A

Design: N/A

Methods: A multi-method feasibility design was utilised. Participants (n = 75) over 18 years, from

the UK, with stage 4 or 5 kidney disease or post-transplant, and who were not currently undergoing psychotherapy, were recruited to the study and participated in the four-week CMR programme. Data was collected at baseline, post-intervention and at three-months post to measure anxiety, depression, self-compassion, mental wellbeing, resilience, and mindfulness. Qualitative interviews were conducted with participants and the Mindfulness Teacher to explore the feasibility and acceptability of the intervention for a kidney disease population.

Results: In total, 65 participants completed the CMR programme. The majority were female (66.2%) and post-transplant (63.1%). Analysis of completed outcome measures at baseline and post-intervention timepoints (n=61), and at three-months post intervention (n=45) revealed significant improvements in participant's levels of anxiety and depression, self-compassion, mental wellbeing, resilience, and mindfulness.

Thematic analysis of participant interviews (n=19) and the Mindfulness Teacher (n=1) identified three themes (and nine-subthemes); experiences of the CMR programme that facilitated subjective benefit, participants lived and shared experiences, and practicalities of CMR programme participation. All participants interviewed reported that they found participating in the CMR programme to be beneficial.

Conclusion: The findings suggest that the CMR programme has the potential to improve psychological outcomes among people with advanced kidney disease. Future randomized controlled trials are required to further test its effectiveness.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 4

Roles and responsibilities of the community palliative care key worker

Topic: Community based approaches to palliative care

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Background: The role of the palliative care key worker was introduced to enhance patient-centred care and is a fixture across health and social care systems. Variances in the role and a lack of understanding on the responsibilities were identified, prompting this review.

Objectives: The aim of this review was to provide an overview of the existing literature on the roles and responsibilities of a palliative care key worker.

Design: Given the lack of existing systematic reviews of the evidence base, a scoping review was considered the most suitable design.

Methods: From a search undertaken in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines for scoping reviews, five papers were identified.

Results: Two themes were evident: perceptions of the role regarding barriers of the implementation in practice. Uncertainty about the role, operationalisation of the key worker, and differing views about who should occupy the role were evident in these studies.

Although participants in selected studies understood the importance of care coordination in palliative home care, issues around communication and training, and uncertainty around the key worker role appeared to be barriers to implementation.

Implementation of the key worker role was inconsistent, signifying a lack of standardisation and adherence to policy guidelines. Those allocated the role did not see a difference in their existing role, nor did it impact the time spent with patients, but it did result in additional paperwork.

Conclusion: The lack of research and understanding of the role is operationalised in practice. The role is advocated for continuity of care; however, uncertainty regarding who should adopt this role was evident, and barriers underpinning the implementation of the role in practice were reported. Further research is warranted to improve understanding on how the key worker

role can be effectively translated from policy to practice.

Trial Registration (if applicable)

N/A

Abstract ID: 5

How shared decision-making, via the Professionally-Driven Zone of Patient or Surrogate Discretion, can improve palliative care and decrease decisional conflict

Topic: Public Health Palliative Care

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Background: When exploring existing shared decision-making (SDM) models, it is evident that there are significant challenges that can limit shared decision-making's successful implementation in palliative care. To address these challenges, a novel model of SDM is needed.

Objectives: This presentation undertakes a critical examination of the concept of "Shared Decision-Making" (SDM) by exploring current understandings of what is meant by the term. A harm-threshold approach is proposed, in part, to navigate a way forward in palliative care decision-making with what is termed the Professionally-Driven Zone of Patient or Surrogate Discretion.

Design: N/A

Methods: The Professionally-Driven Zone of Patient or Surrogate Discretion aims to define the scope of participant roles in SDM better than existing models. It looks to better understand the normative weight both autonomy and paternalism ought to carry in medical decision-making, and ensures that the treatments or interventions which are pursued in SDM are chosen from a range of ethically-defensible options that respect the rights of patients, and limits of medical interventions.

Results: N/A

Conclusion: A Professionally-Driven Zone of Patient or Surrogate Discretion is a broadly-applicable model of SDM that takes a harm-threshold approach, rather than appealing strictly to best interests. This model avoids or addresses many of the challenges that impede successful

implementation of other SDM models, and can both strengthen palliative care decisions, as well as decrease decisional conflict in practice.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 6

Community Palliative Care Patients Experience of EMPOWER: an Occupational Therapy (OT) self-management anxiety group programme

Topic: Health promotion and palliative care

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Background: Anxiety is a significant barrier to engaging in meaningful occupations. Self-management combines education and goal setting to promote and support individuals to make positive behavioural changes to their health. EMPOWER, a four-week group programme, provides self-management interventions for stress and anxiety. Due to Covid19, EMPOWER was adapted virtually and returned to face-face once restrictions were lifted.

Objectives: EMPOWER provides self-management education and goal setting to encourage behavioural changes and promote self-efficacy to help participants manage stress and reengage in meaningful occupations.

Design: A qualitative descriptive design study was conducted with those who participated in EMPOWER to ascertain their acceptability of the programme.

Methods: Community-based palliative care patients were invited to attend EMPOWER. Qualitative focus groups or feedback forms were facilitated and completed post-intervention. Data were analysed using thematic analysis.

Results: Six virtual and five face-face EMPOWER programmes were facilitated from January 2020

– December 2023 with a total of 25 participants. Qualitative data analysis identified three main themes;

- 1) Living with Symptoms,
- 2) Management of Symptoms,
- 3) Programme Design and Delivery.

Conclusion: EMPOWER is considered an acceptable intervention by community-based palliative care patients. Improved understanding of self-management skills to manage anxiety, encouraged participants to implement strategies and reengage in meaningful goals. EMPOWER is now offered virtually or face-face, increasing patient access to the programme and specialist palliative care OT.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 7

International maPping exercise of Arts Interventions in reNal uniTs: the PAINT project

Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Many patients living with end-stage kidney disease (ESKD) experience a reduced quality of life, with depression affecting up to one-quarter of patients and a higher prevalence rate for anxiety compared to the general population. The use of the arts to promote and support health and wellbeing has received ongoing attention since the

publication of the All-Party Parliamentary Group on Arts, Health and Wellbeing report in 2017 outlining the benefits of the arts on psychological, social and physical health and wellbeing, and the World Health Organisation 2019 report on the evidence for arts. The Renal Arts Group (RAG) is a collaborative research group, established in 2016, between patients with ESKD, carers, clinicians, academics, and artists to develop a programme of research aimed at developing and evaluating arts interventions to improve the physical and psychological quality of life of those living with kidney disease.

Objectives: Undertake an international mapping exercise to identify the current provision of arts programmes for renal patients co-produced with a consortium made up of members of RAG in partnership with arts programmes based in the Philippines, United States, Ireland and at the World Health Organisation.

Design: The study will undertake a mixed methods approach to identify the current provision of arts interventions in renal units globally.

Methods: An online survey is currently 'live'. A series of semi-structured interviews will be conducted with units identified from the survey to further explore the delivery of arts interventions.

Results: The survey has been 'live' online since mid-January 2023 and preliminary findings of the study will be available for dissemination.

Conclusion: This project will identify policy recommendations for future development of arts in health programmes for renal patients and will provide an overview of what is being offered globally.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 9

The development of a bereavement competency framework for Level 2 service providers

Topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: The Framework for Adult Bereavement Care, based on the public health approach, suggests that people who experience bereavement have needs ranging from acknowledgement and compassion at Level 1 (all bereaved people) to specialist therapeutic support at Level 4 (minority of bereaved people). The framework also identifies supports/services appropriate to meet each level of need and the corresponding knowledge/skills for those providing support. However, there are no agreed standards for bereavement care services in Ireland, nor agreed competencies for service providers at any level of care. Service providers at Level 2 of the Framework provide emotional and/or practical support. The care is provided most commonly by a bereavement support volunteer or by someone in the context of their professional role (e.g. General Practitioner, public health nurse).

Objectives: (1) To develop a CORE Competency Framework for bereavement service providers working at Level 2, and (2) to establish consensus from stakeholders on the relevance of these competencies.

Design: A Delphi methodology was used to identify a consensus view across subject experts.

Methods: A literature review on competence in bereavement care and aligned areas was conducted. Based on this, a survey was developed which presents a list of core competencies. Over two survey rounds, participants will indicate their agreement with the extent to which each statement is a core competency to reach a group consensus. The survey was granted ethical approval.

Results: A review of the literature identified six domains of competency and associated indicators under each domain. Key subject experts (n = 50) were invited to participate in an online Delphi survey in June 2023. The two-round Delphi is due to be completed in August 2023.

Conclusion: This survey forms part of a wider project which will develop an eLearning resource to meet the core competencies identified.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 11

The support needs experienced by patients requesting medical aid in dying and their relatives: a qualitative study using semi-structured interviews and written narratives

Topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: Medical aid in dying (MAID) has become an increasingly prevalent practice at the end of life globally. Persons requesting MAID (patients) and their relatives might experience several difficulties and suboptimal outcomes throughout their MAID trajectories. This may indicate that their support needs are not adequately addressed in practice or are unknown by their healthcare professionals. However, we lack an in-depth understanding of their support needs experienced throughout their MAID trajectories.

Objectives: To explore the support needs that patients and relatives experience throughout their MAID trajectories

Design/Methods: We carried out a qualitative study in Flanders and Brussels (Belgium) in 2022 using 1) semi-structured interviews with and personal written narratives (via qualitative questionnaire) of patients requesting MAID and 2) semi-structured interviews with relatives of patients requesting MAID. Data were collected using purposive and snowball sampling. We performed an interpretative thematic analysis.

Results: Our analysis included the lived experiences of 15 patients requesting MAID and 21 relatives. We identified eight themes or types of support needs that patients and relatives

(participants) had experienced throughout their MAID trajectories. More specifically, participants needed support for 1) maximizing daily functioning (only reported by patients), 2) making sense of the unbearable suffering (only reported by relatives), 3) managing meaningful activities, 4) navigating existential questions, 5) psycho-emotional regulation, 6) facilitating social interaction, 7) understanding the process toward MAID, 8) and handling organizational and practical matters.

Conclusion: Our study reveals that patients and relatives experience multidimensional support needs throughout their MAID trajectories. Moreover, our findings suggest that they experience their MAID trajectories mainly as social-existential processes rather than medical ones. As their support needs align with those encountered in other end-of-life trajectories, MAID support for patients and relatives might benefit from adopting a partially demedicalized, palliative care approach to optimize its effectiveness in practice.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 12

Successful use of dexmedetomidine to allow cooperative sedation and facilitate transformation

Topic: Collaborations between professional and non-professional caregivers

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Background: An 87 years old gentleman who suffered of COPD, arterial hypertension, ischemic heart disease and chronic kidney disease was admitted to hospital. As he became increasingly anxious while desaturating, acutely short breath,

struggling to tolerated CPAP he was referred after 2 weeks to specialist palliative care.

He was a very successful businessman, married and father of 8 children.

Objectives: Analysis of the use of dexmedetomidine, an alpha2-adrenergic agonist with hypnotic properties, as an alternative to classical anxiolytics/sedatives.

Design/Method: Case Report

Results: For the first 2 weeks he responded well to breakthrough doses of Fentanyl and Haloperidol SC and commenced a buprenorphine transdermal patch.

When his respiratory distress increased we started a continuous subcutaneous infusion over 24 hours (CSCI) with alfentanil 2 mg, olanzapine 5 mg and clonidine 75 µg, clonidine increased after 3 days 150 µg. His respiratory symptoms responded well, but his panic attacks escalated. We switched clonidine 150 µg to dexmedetomidine 400 µg CSCI. The dexmedetomidine dose of 0.4 µg/kg/h deescalated the panic attacks.

Initially on classical medication he rejected any conversation about the seriousness of his disease. After switching medication suddenly he engaged openly with his family and staff about his dying. His family observed when on classical medication (Fentanyl, haloperidol, midazolam, phenobarbital) he showed a paradoxical increase of his agitation. They noted he had a controlling personality and would not tolerate when his wishes would not be respected.

Conclusion: His family were amazed that the switch in medication allowed him to talk about his dying and share his emotions with them. They were deeply moved by this transformation which triggered a transformation in themselves. After he died they felt a mixture of deep grief and happiness at the same time.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 13

Is pre-bereavement collaboration between family caregivers and healthcare professionals associated with post-bereavement emotional well-being? A population-based survey

Topic: Collaborations between professional and non-professional caregivers

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Background: Examination of the association between quality of care pre-bereavement and the bereavement process suggests that the quality of collaboration with healthcare professionals in their support of family caregivers may play an important role.

Objectives: To investigate pre-bereavement collaboration with healthcare professionals and its association with emotional well-being of family caregivers of people with serious illness post-bereavement.

Design/Methods: Population-based cross-sectional survey of bereaved family caregivers of people with serious illness (N=3000) who died two to six months before the sample was drawn (November 2019), identified through three sickness funds in Belgium.

Results: Response rate was 55%. As measured by the Positive and Negative Affect Schedule (PANAS), family caregivers scored lower on positive affect (PA) and higher on negative affect (NA) compared to a normative sample. Most family caregivers evaluated the pre-bereavement collaboration with healthcare professionals positively. Family caregivers' evaluation of collaboration with healthcare professionals pre-bereavement was positively associated with PA and negatively with NA, also when controlling for confounding effects of socio-demographic and clinical characteristics of the bereaved family caregiver and the deceased person.

Conclusion: There is a positive association between perceived quality of collaboration at the end of life between healthcare professionals and family caregivers and post-bereavement emotional well-being of family caregivers.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 14

The Bereavement Charter Mark for Employers – a pilot in Inverclyde

Topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: The Bereavement Charter Mark for Employers in Scotland is designed to encourage and support employers to make their workplaces more supportive of bereaved staff.

It was developed alongside a suite of complementary resources designed to support employers, managers and colleagues create more bereavement-friendly workplaces, including the Scottish Bereavement-Friendly Workplaces Toolkit and Employer's Guide to the Bereavement Charter.

Objectives: A pilot was undertaken in Inverclyde to explore whether the new resources were useful to organisations wishing to take practical action to improve employees' experiences of bereavement.

Design/Methods: Employers in Inverclyde were contacted by a Project Lead, who explained the Bereavement Charter Mark and offered to support the organisation through the process of applying. Interested organisations each formed a small working group of employees, who met 4-6 times to explore what changes they'd introduce within their organisation to make it more supportive of bereaved people. Free bereavement training was offered to each organisation. The groups were supported by a Project Lead with reference to the Scottish Bereavement Friendly Workplaces Toolkit. When organisations applied for the Bereavement Charter Mark, their

applications shared information about what changes had been introduced as a result of the project.

Results: Organisations all applied for the Charter Mark and introduced changes, for example:

- local bereavement charter
- bereavement policy
- ‘safe space’
- condolence and back to work form
- staff bereavement training
- bereavement educational film shown to all staff

These five organisations were the first in Scotland to be awarded the Bereavement Charter Mark for Employers.

Conclusion: The Bereavement Charter Mark can inspire organisations to undertake positive change, and the accompanying resources can support employees to make practical improvements. In the pilot, organisations benefited from the support of the Project Lead, and it will be important to observe how/if organisations without this dedicated support progress with the Bereavement Charter Mark.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 15

Bespoke Collaboration of Palliative Care for children with open access to support at home and in hospital

Topic: Collaborations between professional and non-professional caregivers

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Background: Two children aged 15 and 5 years, one with metastatic Ewing sarcoma and one with a high grade neuroepithelial tumour with

extensive leptomeningeal disease were referred to specialist palliative care because of high symptom burden. Weighing up symptom burden and the vital need for using Hickman/PICC line, collaboration of acute and community services was essential.

The families’ wishes were to maintain normal life as much as possible.

Objectives: To stay at home for as long as possible with minimal professional health care input. Access when needed to hospital support for symptom management as a day case or when needed hospital admission when oral medication could not be taken anymore.

Design/Method: These case reports demonstrate how important collaborative planning, good communication, listening, flexibility and diversity are to support these journeys.

Results: The 15 years old girl had rapidly increasing pain levels and towards the end seizures. She availed of 38 direct access visits. For her last 25 days she was hospitalized for the complexity of her symptoms and the level of acute support needed. This was agreed with the girl and her family as she became unable to take oral medication.

The 5 years old girl had rapidly increasing pain and worsening seizures. She availed of 40 direct access visits, 11 overnight admissions for IV medication and respite. For her last 5 days she required hospitalization for symptom management at her request.

An open access plan to the paediatric facility allowed bespoke care for both families. They were effectively supported for 183 / 95 days.

Conclusion: This model of care allowed the two girls to fulfil all their and their families’ wishes. Establishing a trusting relationship, the flexibility of the involved staff, mutual understanding, using the wealthy resources and strengths of all involved delivered effective vital symptom management.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 16

Healthcare Professionals' experience of providing care for people with motor neurone disease (MND) and their family caregivers: A scoping literature review

Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Providing care for patients and families impacted by motor neurone disease (MND) can be challenging for healthcare professionals however, this has received less attention in research literature than the challenges faced by patients and family caregivers. There is a need to explore professionals' experience and the possible impact of this work on their well-being.

Objectives: 1) To identify what is known about healthcare professionals' experience of providing care for MND patients and their family caregivers, 2) to explore what is known about the impact of working with MND on healthcare professionals' well-being.

Design, Scoping literature review.

Method: Data was extracted from electronic databases and grey literature using a piloted data extraction tool and analysed using descriptive statistics and thematic analysis.

Results: Of the 51 included texts, the majority were qualitative (75%), completed in the UK (41%) and published in 2022 (16%). 1652 healthcare professionals were represented from fourteen professions and worked primarily in; hospice/palliative care, community/primary care; multidisciplinary clinics, charity organisations, hospital, or residential care settings.

Themes relate to the extraordinary care required by patients and families living with MND, legal, moral and ethical dilemmas and decisions that require individualised and bespoke communication, the necessity for interdisciplinary collaboration, multidisciplinary team-working and professionals' vulnerability when working alone, satisfaction in having a 'meaningful job', organisational barriers and the emotional impact of feeling overwhelmed, physically and emotionally exhausted and powerless.

Conclusion: This review highlights the complexity of care, level of knowledge and skill required and professionals' vulnerability to becoming stressed, burdened and emotionally exhausted because of their work with people with MND. Positive aspects of their work are also highlighted. These findings will be used to influence future research and emphasise the support required for professionals working with people living with MND and their families.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 17

Getxo ZUrekin : Building the narrative of a Compassionate Community

Topic: Compassionate Communities

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Background: In 2017, the "Foundation X" launched 'X Project' as a compassionate community.

Objectives: To prototype a Social Innovation Platform with the aim of raising awareness and identifying integrated solutions to reshape the experience of palliative, end of life care and bereavement.

Design: Network mapping and delivering campaigns, training sessions for carers and the public on how to care in illness through to the end-of-life and support in bereavement. We designed collaboratively and prototyped a community listening platform focused on better understanding the social dynamics and perceptions that local citizens and institutions have on death, illness, and bereavement.

Method: This "open innovation process" includes a listening phase identifying the most significant narratives, collective interpretation sessions, combined with co-design sessions to

identify integrated solutions and improvement opportunities through a co-design/co-production theoretical framework. This process has established a solid foundation for co-creating new integrated solutions, aligned with the socio cultural characteristics of the community.

Results: In the congress we will describe the methodology used for this research and how it is applicable to any area looking for change in integrated care in palliative care. We will also show how grassroots movements being aligned with local institutions can influence in policies thus improving the experience of death, dying and bereavement for all, understanding that to design new solutions, innovative community listening approaches need to be prototyped.

Conclusion: The project has given us real insight into what change the community feels is necessary to allow people to be where they want to be in times of illness and at the end of life.

The listening platform has allowed us to build a shared vision and a narrative of change influencing in public policies and understanding strengths, challenges, and priorities as well as to set up specific priorities and actions in the community.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 18

Who is more death literate – bus drivers or students? A pilot of the Death Literacy Index in Scotland

Topic: Death and grief literacy

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Background: Death Literacy has been defined as: “the knowledge and skills that people need to make it possible to understand, and make informed choices about end of life and death care options”

Originally developed in Australia, the Death Literacy Index (DLI) is designed to measure death literacy within populations with hopes that it can help inform targeting of future interventions to address gaps in death literacy, measure the impact of interventions, and make comparisons across different communities.

Objectives: To explore death literacy in the context of two distinct groups: students and bus drivers.

Design/Methods: The DLI questionnaire gathers information about four key areas: Practical Knowledge; Experiential Knowledge; Factual Knowledge; Community Knowledge.

University students and bus drivers were emailed inviting them to participate in the survey in return for an Amazon voucher.

Results: 20 University Students and 40 bus drivers completed the DLI online. The group of bus drivers had a higher death literacy score than the group of students. This is likely to be due, at least in part, to the higher average age of the bus driver group, suggesting that death literacy increases with age.

Conclusion: The survey sizes were too small for us to allow firm conclusions to be drawn. However, analysis of the questionnaires indicated that:

- People who have experienced grief or other significant life events often feel more prepared to cope with, and help others through, similar events in the future.
- Some people feel very able to have conversations with others about death and bereavement, while others feel unable to talk about these issues – there’s no ‘typical’ level of comfort in talking about death.
- While most people know what a ‘will’ is, there’s a general lack of awareness of other ways that people can plan ahead and get support with death, dying and bereavement.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 20

Family Caregivers' Lived Experiences of Transitioning during End-of-Life Care

Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: For those who choose to spend their remaining weeks and days at home in the terminal phase of illness, the care and support of a family caregiver are usually needed. This role of caregiving can be highly stressful and emotionally challenging. It can also be rewarding. During this time of caregiving, family caregivers respond or react to the deteriorating health of the person who is dying. These responses or reactions are known as transitions. From the time a terminal diagnosis is made to the moment of death, family caregivers, in this context, experience at least one and often multiple transitions.

Objective: Aim: To gain a deeper insight into how family caregivers experience transition during end-of-life care.

To determine the various roles of family caregivers during transitioning. To identify phases of transitioning that family caregivers experience during this time. To understand the meaning of being in transition and to provide knowledge of this experience. To investigate any issues that arise during transitioning for family caregivers. To identify any factors that enable family caregivers as they transition.

Design: A Hermeneutic Phenomenological Approach using one-to-one interviews to collect data from family caregivers was used. The teachings of Heidegger and Gadamer guided the methodological framework.

Results: Preliminary findings of this study show that family caregivers respond in different ways to the declining health of the person for whom they are caring. Themes that emerged from the data collected comprise vulnerability, loss, love, and coping strategies.

Conclusion: Family caregivers experience transition(s) from the time a terminal diagnosis is received to when death itself occurs. This insight into how these caregivers respond or transition is

a valuable opportunity to identify their care needs and in doing so develop appropriate supports to make these transitions less difficult.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 21

Truacanta: A Scottish Compassionate Communities Project

Topic: Compassionate Communities

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Background: The Truacanta Project supported five local communities in Scotland to take action to improve people's experiences of death, dying, loss and care. The project was grounded in a community development approach.

Objectives: Participating communities set out their own desired outcomes for their local projects. At an overall project level, it was hoped that people within the Truacanta communities would gain increased knowledge, information, confidence, skills and opportunities around declining health, death, dying and bereavement.

Method: A dedicated Project Manager post provided community development support and advice to the five Truacanta communities for three years. Communities could access small grants of up to £600 per quarter and the project hosted networking meetings for peer support, knowledge sharing and learning. Each community project decided its own goals and approach. An independent evaluation was undertaken by Janet Biggar Research, based on depth interviews and reflective workshops and attendance at key Truacanta events.

Results: The five communities had different experiences, reflecting their different situations and approaches. The Covid19 pandemic had a huge impact on people's plans, activity and methods. Most communities felt they had made

progress in building local networks, knowledge, confidence and skills around death, and that the support, networks and resources provided by the Truacanta Project had assisted them with this.

Conclusion: The Truacanta Project was valued by participating communities for bringing motivation, resources, practical support, peer support, credibility, learning and networking opportunities.

The project brings important learning for those interested in the use of community development approaches within a public health approach to palliative care. Communities are integral to improving people's experiences of death, dying, loss and care. However, communities themselves have limited capacity and interest, so the complementary supportive role (and potential financial input) of third sector, statutory and private sector remains integral to achieving improvements.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Oral presentation

Abstract ID: 23

The co-design of an advance care planning education resource- ensuring a human rights-based approach

Seminar topic: that abstract is being submitted to: Community based approaches to palliative care

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Background: Engagement in the Advance Care Planning (ACP) process is influenced by knowledge and awareness of what is involved, ensuring

that those taking part -both healthcare professionals and patients/family carers - can comfortably and confidently engage in the process. Education is needed to promote and engage in ACP.

A Human Rights-Based Approach (HRBA) to ACP should emphasise a person-centred approach, informed decision making (based on patients' core values), and equity of access to the process. Implementation of a HRBA should consider the 'rights holders' (patients and their ability to exercise their rights) and 'duty holders' (health care professionals and their responsibilities). Patient and public involvement (PPI) provides the opportunity to ensure the opinions of both are considered and thus the rights of those involved in the process.

Objectives: The primary objective of this project is to co-develop an ACP digital education resource with, and for, community nurses, patients, and family carers.

Method: Phase 1 includes n=4 co-design workshops (n=2 including community-based nurses and n=2 including patient and family carers). Mapping of the co-design process, with the National Human Rights Institute's five key human rights principles (Participation, Accountability, Non-discrimination and Equality, Empowerment and Legality (PANEL)) will demonstrate how PPI can contribute to a HRBA in an ACP context.

Results: At the time of this conference, phase 1 will be complete and results presented to demonstrate how a co-design approach contributes to the development of a HRBA to ACP.

Conclusion: The importance of adopting a HRBA in ACP has been highlighted within the literature with input of the 'rights holders' and 'duty bearers' as essential. It is anticipated that PPI will increase transparency of the research process, facilitate accessibility of information and education, and contribute to fairness in the delivery of the process ultimately contributing to a HRBA in the ACP process.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 24

Online forums support palliative and bereavement care: machine learning and natural language processing analysis of qualitative data from the internet

Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Recent challenges for palliative and bereavement care have included precarious funding, inconsistent availability, and service disruption caused by the Covid-19 pandemic. Digital services may circumvent these challenges, allowing people to self-manage their needs.

Objectives: To investigate how community-led online forums are used to support people facing life-limiting illness, their caregivers, and bereaved people.

Design: We utilised machine learning, Natural Language Processing (NLP), and Inductive Thematic Analysis (ITA) to obtain and qualitatively analyse written online forum data.

Method: We web-scraped forum posts, and used NLP Clustering, Classification, and Surprising Phrase Detection to exclude irrelevant data and categorise included data. We utilised ITA to generate themes.

Results: We analysed 7048 forum posts from 2003-2020 and found online forums facilitated people receiving psychosocial support of better quality and greater duration than what was available elsewhere, and compensated for deficiencies in systems, especially during the Covid-19 pandemic. Care systems were largely perceived as inadequate and disempowering by forum users, while online forums themselves acted as solutions, including increasing users' sense of empowerment, providing information on legal rights and benefits which may not be otherwise easily available, and facilitating collective advocacy.

Conclusion: Online forums developed and led by patients and carers can play an essential role in providing information and support,

democratising care, and retaining agency when facing life-limiting illness and grief. Online support forums may therefore provide an effective and sustainable means to support people in meeting their needs, although they are not yet widely acknowledged as adjunctive to mainstream palliative and bereavement care. Future palliative and bereavement care research must focus on how online forums can be integrated into existing systems, made transparent and accessible to all who need them, be optimally funded and structured, and be used to provide consistent support, including compensating for service disruption encountered during future pandemics.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 25

Examining a human-rights based approach in the development and implementation of The National End of Life Survey

Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Respecting and protecting human rights, basic rights and freedoms inherent to all humans, in end-of-life care is crucial due to the vulnerability of people in receipt of end of life care, who may not be able to advocate for themselves. The FREDAs principles (fairness, respect, equality, dignity and autonomy), are an internationally recognised framework for upholding human rights in healthcare.

Objectives: The National End of Life Survey (NELS) is the first national survey to explore experiences of end of life care in Ireland from the perspectives of bereaved relatives. This study assessed the extent to which the survey design, development and implementation aligned with a human-rights based approach to end of life care.

Design: The study involved mapping the survey questions and themes to FREDa and the relevant articles from the European Convention on Human Rights (ECHR) Act 2003. The extent to which human rights were considered in the survey's development and implementation were also explored.

Results: The questionnaire contains several questions and themes relevant to FREDa. Questions asking about the provision of pain relief, emotional support, being offered adequate privacy, and being involved in the decisions about their care and support at the end of life, aligned with FREDa principles of human rights, and the ECHR Act 2003, Articles 3, 5, 8 and 10. A human rights focus was embedded in the survey's implementation in areas relating to respect for private and family life, freedom and expression, freedom of thought, conscience and religion, and prohibition of discrimination.

Conclusion: By mapping the survey questions to FREDa, this study facilitates exploration of how human rights are respected and fulfilled at the end of life, using a large national survey of experiences of end of life care.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 26

Patient Support Programme – An Experience in a Tertiary Cancer Centre in North East India

Topic: Community based approaches to palliative care

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Background: The Home care service of the tertiary cancer institute covers the patients within a radius of 70kms. It is seen that most of the home care patients do not complete their curative treatments offered by oncologists. On enquiry, patients

and relatives cite the financial crisis as the most common cause. To support them financially, Home Care Patient Support Program (HCPSP) is started with the help of a corporate organization.

Objectives: The aim of the study is to find the impact of HCPSP in relation to completion of treatment for lower categories of patients.

Design/Method: This is an observational study. The socioeconomic status (SES) of home care patients were evaluated with the help of Kuppaswamy Socio-economic Scale. Upper lower, lower middle & lower-class families were selected for the HCPSP. Patients were supported for all investigations, medications and hospital charges. The patients were followed up in next home visits and assessed for completion of investigations/treatments.

Result: A total of 746 patients received home care service till 31st Dec, 2022. 411 patients were evaluated for SES by Kuppaswamy scale at the time of first home visit, of which 245 were found to be in Upper lower, lower middle & lower-class categories. A total of 77 patients were selected randomly and offered financial help for various examinations and treatments. A total amount of Rs.3,94,429/- utilized for the scheme. Number of patients received financial support for investigations-34, admission/hospital charges-25, radiotherapy-4, chemotherapy medicines-20, supportive medicines-18. All the patients were followed up for two months. It was found that 72 patients (93.5%) completed their treatments.

Conclusion: The HCPSP provided solutions for financial strains of the patients and thereby enhanced treatment adherence. India being a developing country, there is a need for more schemes to support patients on healthcare expenditures.

Trial Registration (if applicable)

N/A

Abstract ID: 29

Transforming Palliative Care in Colombia through a comprehensive patient-centered strategy using an individualized Holistic Needs Assessment Tool

Topic: Engaging and working with patients, informal caregivers and citizens to shape

palliative and end of life care, caregiving and bereavement

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Background: Despite marked developments in palliative care in Colombia over this last decade, there remains fragmentation in relation to the integration of palliative care into chronic illness management, hampering the provision of optimal care (Reid *et al*, 2021). This project builds on our previous work which includes the Sheffield Profile for Assessment and Referral for Care (SPARC) being translated and validated to a Colombian-Spanish version (SPARC-Sp).

Objectives: This project aimed to co-design a strategy to: (1) emphasise the importance of a holistic needs assessment to identify individual supportive and palliative care unmet needs; and (2) inform the implementation of a needs assessment tool (SPARC-Sp) across care settings within Colombia.

Design: The UK based team (Queen's University Belfast and University of Sheffield) and Colombian-based collaborators at Universidad del Cauca and Pontificia Universidad Javeriana delivered a series of seven co-design workshops in 2022/2023. Of these, three were online and four were in-person (both rural and urban areas). Attendees at all co-design workshops included key stakeholders such as patients, carers, health-care professionals, volunteers, non-governmental organisations, finance administrative staff and policy makers.

Method: N/A

Result: The workshops explored the current palliative care provision and co-designed an implementation strategy for SPARC-Sp within the Colombian palliative care pathway. Responsive to information shared at the workshops around patient / healthcare professional requirement for education in relation to both palliative care and SPARC-Sp, we co-designed a series of five videos. These will act as educational tools and will be incorporated into future research.

Conclusion: This project has co-designed an implementation strategy for SPARC-Sp, to identify patients with unmet supportive and

palliative care needs who would benefit from timely, holistic needs assessment and associated care provision. This work will form the foundation for a future large-scale funded research project focusing on the implementation and evaluation of SPARC-Sp within Colombia.

Trial Registration (if applicable)

N/A

Abstract ID: 30

A systematic review of educational interventions to equip health and social care professionals to promote end of life supportive care when a parent with dependent children is dying with cancer

Topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: Adults with advanced cancer that have dependent children (>18) want guidance to communicate with their children when death is imminent. Health and social care professionals (HSCPs) are ideally placed to provide this aspect of care but lack the skills, competence, and confidence to do so due to insufficient training. This has a detrimental impact on the delivery of family-centred care and an adverse psychological impact for the family unit.

Objectives: To systematically review the literature to determine the content, mode of delivery, assessment and outcomes of educational interventions to equip HSCPs when delivering end of life supportive care for adults dying with cancer who have dependent children.

Design: The review was conducted according to the Joanna Briggs Institute's mixed methods review methodology.

Method: Six electronic databases (Medline, OVID, CINAHL, EMBASE, PsycINFO, Web of Science and ERIC) were searched and grey literature searches of Google Advanced Search and relevant professional bodies were conducted. Extracted data relating to content of educational interventions, mode of delivery, assessment and

evaluation of educational interventions and outcomes were analysed, narratively.

Results: Eligible studies were identified, highlighting the dearth of educational interventions available to HSCPs to provide supportive care to families when a parent is at end of life (EoL) with cancer. The identified interventions were of good methodological quality and were positively evaluated by participants, enhancing their confidence to engage in EoL conversations.

Conclusion: The review highlights the urgent need for the development of interventions for HSCPs to provide supportive care to families when a parent is at EoL with cancer. This is a fundamental aspect of care and it is imperative that accessible educational interventions are developed to improve the quality of care and reduce distress for patients and their families.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 32

“One chance” - SWAN End of Life (EoL) and Bereavement Care model

Topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: Instigated at the point of recognition of dying, distinguished by a swan symbol, it supports care throughout EoL, into bereavement and beyond. Adopted in over 60 health and social care organisations, throughout the UK, SWAN is an example of best practice.

Objectives: Providing high-quality, individualised EoL and bereavement care for every patient, every family, every time.

Design: SWAN aligns EoL, bereavement care and organ donation enabling everyone to access equitable, high-quality care, regardless of diagnosis or circumstances. It recognises the importance of care in circumstances where death is expected as well as sudden/unexpected death. A person/family-centred approach to care is given before and after death. Individualised bereavement care and support for families, including memory-making and meeting faith needs is facilitated by all staff, irrespective of clinical specialism or position.

Method: The SWAN model is based on the values of discretion, kindness, respect, dignity, and compassion. Sustainability of the SWAN is achieved through high-level organisational support creating a culture which prioritises and normalises EoL and bereavement care. Empowered staff deliver consistent, high-quality care, supported by regular education, training and real time coaching. Patient and family feedback is actively sought.

Results: SWAN improves EoL/bereavement care, empowers staff, impacts positively on organisational culture, is a recognisable standard of quality for CQC and is easily transferrable to different ages, circumstances, and settings.

It is flexible, evolves to meet need and offers an inclusive approach working with different professionals and staff groups across organisations, promoting networking and best practice.

Conclusion: SWAN offers a consistent, equitable approach, which can successfully support improvements in standards of EoL and bereavement care, nationally and internationally.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 36

The right to refuse: Awareness of Advanced Directives in a cohort of patients with cancer

Topic: Engaging and working with patients, informal caregivers and citizens to shape

palliative and end of life care, caregiving and bereavement

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Background: Advance Care planning allows patients to document their preferences for care as their illness progresses – including the acceptance or refusal of certain interventions. In April 2023, Ireland enacted the Assisted Decision Making and Capacity Act – which gives legal protection to Advance Care Directives (ACDs).

Objectives: Our pilot study sought to assess, within a cohort of oncology patients, knowledge of and opinions towards Advance Care Directives.

Design: This pilot was completed in a tertiary hospital over a four week period. All inpatients under the medical oncology service were considered for inclusion. Exclusions were patients with cognitive issues, limited life expectancy (<60 days), unstable illness, and severe anxiety.

Method: Completion of a questionnaire was facilitated by a doctor known to the patient to help explain the components. Analysis of the results was completed by a doctor not involved in the interview process.

Results: A total of 30 patients were surveyed, out of 125 inpatients during the survey period. Reasons for exclusion included cognitive issues (n=30), short prognosis (n=18) and anxiety (n=12). No patient included had an advance directive; 17% (n=5 patients) were aware of their existence. No patients were aware of the new Irish legislation. 87% (n=26) would consider making an ACD. Regarding healthcare decisions, 30% (n=9) would allow their treating Oncologist to fully guide their decisions (refusal of ICU, etc.) whereas 70% (n=21) would make their own decisions.

Conclusion: Our study shows that while awareness of ACDs is low, most patients are willing to engage in a discussion. The high number of patients excluded due to cognitive issues or acute illness suggests that clinicians are perhaps leaving it too late to initiate this discussion. We plan to disseminate these results within the department to prompt early consideration of advance care planning.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 38

Empowering Physiotherapy for Oncology With Exercise and Rehabilitation in people with metastatic breast cancer (EMPOWER-Breast), a physiotherapy-led service in a primary care setting. A Qualitative study with physiotherapists and people with metastatic breast cancer

Topic: Palliative care and underserved populations

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Background: The expectation, experience and needs of people with Metastatic Breast Cancer (PwMBC) and physiotherapists working in primary care, acute specialist care and palliative care in relation to a physiotherapy-led service in a primary care (PC) setting is unclear.

Objectives: We explored, using a qualitative design in a series of three focus groups discussion (FGD), the experiences, needs, perceived barriers and facilitators for a new PC physiotherapy-led exercise programme EMPOWER-Breast, through engagement with PwMBC and physiotherapists working in primary care, acute specialist care and palliative care.

Method: Guided by interpretative description methodology, using a theoretical domains framework (PRISM framework) our qualitative study consisted of three FGD with four Irish PwMBC, fourteen physiotherapists working in primary care and acute specialist care and four physiotherapists working in palliative and acute specialist care in Ireland. The FGD was transcribed verbatim and analysed inductively using the 6-step process described by Braun and Clarke, 2006. We used the three domains of COnsolidated criteria for REporting Qualitative research (COREQ)

Reporting of qualitative analysis and Bazeley's Explicit (Describe, compare, relate) to further interpret and integrate the results.

Results: Participants discussed in detail the elements of the proposed intervention that were important to them as well as the barriers, facilitators and the desired outcomes of the proposed intervention. They highlighted the need for training opportunities for staff to facilitate clinical expertise, robust information and communication exchange strategies and agreed pathways of care for bidirectional referral, in the design and implementation of the proposed intervention.

Conclusion: The experience and needs of stakeholders are essential components to consider in the design and implementation of EMPOWER-Breast. We will use these results and to inform a co-design process involving participants and service managers and the oncology multidisciplinary team.

Trial Registration (if applicable)

N/A

Funding Support

Joyce MCV O' Riordan is supported by a scholarship from the Government of Ireland Irish Research Council EBPPG/2021/98

Conflict of Interest

None

Abstract ID: 41

Bereavement Support and Grief Education in Schools: A Child Rights Obligation

Topic: Bereavement - End-of-Life care and bereavement care policies; public health interventions; bereavement literacy

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Background: The United Nations Convention on the Rights of the Child (UNCRC) is international law that sets out rights of under 18-year-olds in relation to protections, provisions and

participation. The NI Government has a duty to ensure these rights are realised in law, policy and practice. However, not all children have access to bereavement support in school and grief education is not mandatory. This is despite most children experiencing the death of someone close to them by the time they leave school.

Objectives: To consider a School Bereavement Programme from a rights-based perspective and reflect on the wider value of using a rights framework when designing and describing public health approaches.

Method: A desk-based exercise was conducted to consider which Rights are engaged through a pilot School Bereavement Programme which has been developed for and with children and young people, and which aims to build competency in teachers and grief literacy in children through the delivery of teacher bereavement training and a teacher-led lesson plan.

Results: The pilot programme engages a number of Articles of the UNCRC in its design, delivery and evaluation. Children's voice (Article 12) and best interests (Article 3) are a central focus in its oversight, planning and monitoring. The outputs from the programme are designed to be age and developmentally appropriate (Article 2, 6). And the anticipated impact is for it to ensure that health and wellbeing (Article 24) and child-centred and empowering education (Article 28, 29) are given equal importance by Government and Schools.

Conclusion: Applying a children's rights perspective to bereavement support interventions in schools and grief education provision provides an alternative way of demonstrating the holistic benefits such public health approaches offer and highlights the obligations on Government to address unmet need and through such actions realise children's fundamental rights.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 44

Experiences of Healthcare Providers and Bereaved Next of Kin Relating to the Provision of Palliative Care in Adult Intensive Care Units in Saudi Arabia

Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Palliative care provision in intensive care units (ICUs) is a complex and challenging issue that requires careful consideration of the needs and experiences of both healthcare providers (HCPs) and bereaved next of kin (NoK). There is paucity of evidence from HCPs and Bereaved NoK in relation to palliative care (PC) delivery in adult intensive care units (ICUs), especially in the Kingdom of Saudi Arabia (KSA).

Objectives: The aim of this study was to obtain the views of key stakeholders including HCP and bereaved NoK of patients with regard to palliative care provision in adult ICU settings.

Design: A purposive sample of 9 HCPs and 11 bereaved next of kin of patients participated in this qualitative study. A semi-structured interview guide was used to collect data through telephone and virtual interviews.

Method: The data collected from the interviews were analysed using a thematic analysis framework, NVivo software was used to manage the research data. The researcher identified patterns and themes in the data that helped to make sense of the participants' interpretations, views, and experiences of palliative care in ICUs.

Results: Thematic analysis of the HCPs and Bereaved NoK generated three overarching themes including: (i) Barriers to Palliative Care Provision in ICU, (ii) Communication among healthcare providers and bereaved next of kin related to palliative care and (iii) Future directions and recommendations to optimise palliative care in ICU.

Conclusion: Palliative care should be integrated into the adult ICU settings to benefit key stakeholders including staff, patients, and their

families. The information generated from this study will assist hospital administrators in the formulation of effective strategies to properly implement PC in adult ICUs.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 50

Bereaved Caregivers' Experiences of End of Life Care For People With Advanced Heart Failure: A Narrative Synthesis

Seminar Topic: Engaging and working with patients, informal caregivers and citizens to shape palliative and end of life care, caregiving and bereavement

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Background: Heart Failure is a life-limiting condition with a poor and uniquely unpredictable prognosis. Prior research has indicated that end-of-life care can improve symptom management and decrease caregiver burden.

Objectives: The aim of this review is to present and synthesise the current evidence around bereaved caregivers' experiences of end-of-life care for people with Heart Failure.

Design: A systematic review of the literature was undertaken.

Method: A search of the literature was conducted using four electronic databases (CINHAL, Medline, BND, PsycINFO). Research published between January 2020 – September 2022 that focused on bereaved caregivers' experiences of end-of-life care for people with Heart Failure was included. Data was analysed and presented using a narrative synthesis approach.

Results: Eight articles were critically appraised and included in this review. Themes included: Limited and inadequate communication around the condition (including prognosis, preparations for death, and the aim of palliative care), the

burden of caregiving, and the limited provision of services and formal support.

Conclusion: Bereaved caregivers experience unique and significant challenges when caring for someone dying from Heart Failure. However, the paucity of research obtained in this search indicates that further research is required to greater understand the experiences of bereaved caregivers of people with Heart Failure.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Abstract ID: 78

'Living Matters Now': Improving transitional care for young people with complex and life-limiting conditions

Seminar Topic: Palliative care and underserved populations

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Background: The number of children and young people in the UK with life-limiting conditions is increasing and many of them are living much longer than in the past. As young people mature, their needs and preferences change, meaning the models of care used to support them need to be adapted. When this does not happen, young people may disengage from services and experience poor outcomes in their health, social participation and education.

Objective: To improve the care and experiences of young adults with complex and life-limiting conditions, with a focus on improving the 'transition' process young adults undergo when moving from children's to adults' palliative care services.

Design and/or Method: Leading a national community of practice, supporting the development of regional hubs and listening to young people with lived experience.

Hospice UK ran a three-year programme, supported by the DD McPhail Charitable Settlement, from 2019 to 2022. This included: leading and developing a national network for Transition Co-ordinators, supporting the establishment of three regional ECHO hubs and producing online resources for professionals involved in transitional care for young people. The project engaged with young people with lived experience of transitional care to hear what they valued.

Results: Despite disruption due to the COVID-19 pandemic, the programme engaged with professionals and young people with lived experience to achieve the following:

New web resources to support those caring for young people transitioning to adult services

Supporting the updating of national transition resources

Sharing learning and building lasting networks to drive improvements in care

Conclusion: This programme reinforced the critical importance of listening to the expert voice of lived experience as a foundation for improvement projects. Really hearing, what it is that young people, as well as professionals, have to say is central to how we will deliver lasting and meaningful change.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

Presentation Type – Oral or Poster, Poster Presentation

Abstract ID: 93

Southern PEARL

Topic: Public Health Palliative Care

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Background: Providing further education on palliative and end of life care (PEOLC) is a key

priority within the Southern Health & Social Care trust (SHSCT). However, multiple services and professionals across the SHSCT highlighted the need for standardised education in this area with specific gaps identified and other areas having multiple sources of information which at times can be contradictory or confusing.

Objectives:

1. To provide an accessible, educational resource for professionals in key areas related to PEOLC.
2. To use the same format to provide an accessible, educational resource for service users in relation to PEOLC, to help with understanding what is available and set realistic expectations.

Design and/or Method, A collaborative, qualitative approach was used with multiple specialist teams designing a combination of presentations, videos and other educational resources on key areas of PEOLC. The key areas identified were obtained from questionnaires shared with teams across the SHSCT to identify areas they feel they require further training.

Results: Following collection of the areas that further training was required, the specialist teams compiled training resources reflective of their working area. The resources were compiled on a digital platform which is accessible on both computer and SMART phones increasing accessibility to the resource. The resource was named Southern PEARL (Palliative Education and Resource Library). To enhance accessibility it can be viewed by clicking a URL or scanning an associated QR code.

Conclusion: Feedback from across the SHSCT in both primary and secondary care has been positive in relation to the accessibility of standardised information in relation to PEOLC. From its release the resource has been accessed approximately 2000 times and is still used on a daily basis with an increasing number of services requesting access to it. Work is now underway to finalise the public facing version.

Trial Registration (if applicable)

N/A

Abstract ID: 95

Does 'Necessary Discussions' support a human rights-based approach? Evaluating a digital Advance Care Planning Resource for nursing home staff and family carers

Topic: Death and grief literacy

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Background: Necessary Discussions is an Advance Care Planning (ACP) digital education resource developed for nursing home staff and family carers of residents with advanced dementia during a COVID-19 outbreak. This resource provides information to support discussions around goals of care at the end of life. The ACP process may align with the human rights principles of fairness, respect, equality, dignity, and autonomy (FREDA). These principles represent the basis of good clinical practice.

Objectives: To examine how Necessary Discussions aligns with a human-rights based approach by mapping the FREDA principles.

Design and/or Method, A detailed mapping review was conducted into each component of Necessary Discussions with the FREDA principles (fairness, respect, equality, dignity, and autonomy). This was completed by two independent reviewers, who reviewed resource modules independently. Where differences emerged, it was arbitrated in a team meeting involving a third reviewer.

Results: Current work is ongoing. Findings will help evaluate if the Necessary Discussions resource aligns with the FREDA principles, considering the virtue of a human rights-based approach and highlighting the strengths and challenges in actualising this approach.

Conclusion: We anticipate this work will provide a framework to consider a human-rights based approach within an ACP education resource and highlight important considerations in the process. Lessons that stem from this project will inform ongoing work as Necessary Discussions is scaled out to other populations. Future interventions would benefit from considering human rights

principles from the developmental stage and could be supported by co-design.

Trial Registration (if applicable)

N/A

Finding

N/A

Conflict of Interest

None

Abstract ID: 103

Show, don't tell: how can we present public health palliative care information visually?

Seminar Topic: Public Health Palliative Care

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Background: During the Covid pandemic, there was an increase in visual technology in healthcare with 'dashboards' becoming familiar to healthcare professionals as well as the general public. This has accelerated the use of healthcare data visualisation where diverse medical data, often from different sources, is collated into a user-friendly format. Examples of healthcare data visualisation include infographics, interactive maps, live dashboards and animation. For healthcare professionals, improving data interpretation and decision making has obvious clinical, operational and strategic benefits. Healthcare data visualisation may also prove helpful in communicating key messages to non-medical stakeholders (eg government and political parties) and the public.

Objectives: Our objective was to collate pre-existing palliative care data for our local area and present it in an infographic-style format. This can be used to better understand the palliative needs of our local population and guide operational and strategic development.

Design and/or Method: Data was sought from a range of sources, firstly from local and secondly from regional sources (if no local data available). The infographic included data such as location of adult deaths, General Practice/ District Nurse/ community pharmacy assess, and specialist palliative care access.

Results: With a wide range of palliative care data available, choosing useful and relevant information to best understand the needs of the local population is key. However the infographic format itself limits detail and in part, dictates the data used. The infographic will need further developed after real-world use and feedback.

Conclusion: Healthcare data visualisation provides another medium for communication of data however this will need properly resourced by organisations as the skills to create these images are unlikely to be found within healthcare teams. Healthcare data visualisation is a developing area and offers an exciting new communication medium to present palliative and public health information to a wider audience.

Trial Registration (if applicable)

N/A

Funding

N/A

Conflict of Interest

None

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