Committee for Health Inquiry – Review of access to palliative care services

Dr Lisa Graham-Wisener

Reader in Health Psychology, Queen's University Belfast

[redacted]

Professional background: Chartered psychologist, employed at QUB for 6 years, previously Research Lead for Marie Curie Hospice Belfast for 3 years. PhD in psycho-oncology.

Aligned to your inquiry's objectives, I have summarised key pieces of evidence below and have hyperlinked to an open-access version of all research papers and reports. I have indicated where data collection has been conducted within Northern Ireland (NI).

PUBLIC UNDERSTANDING OF PALLIATIVE CARE

Death Literacy

Death literacy includes the knowledge and skills that people need to gain access to, understand, and make informed choices about end of life and death care options. I have written a lay explainer on this for the Conversation.

Death literacy needs to be a key consideration when seeking to improve access to palliative care services, and overall quality of care. A population with a high level of death literacy will understand what palliative care is and the options available to them and/or their family, will be better supported to make proactive and informed decisions around their care, and will be more able to clearly communicate their wishes to healthcare professionals and others.

Death literacy is an increasingly key area of focus both regionally and nationally. For example, it was recently discussed as part of the parliamentary debate on assisted-dying where the Health and Social Care Committee recommended the UK Government establish a national strategy for death literacy. Death literacy is a core tenant within the new public health model of palliative and end-of-life care which we need to develop in NI, and is discussed within the Lancet Commission on the Value of Death.

The evidence summarised below suggests that there is significant need to increase death literacy for our population and suggests the need for a dedicated workstream on enhancing death literacy under a new palliative care strategy for NI.

Measuring and benchmarking death literacy

Measuring and benchmarking death literacy is important aspect of developing targeted initiatives, which are aligned to a population's needs.

The Death Literacy Index (DLI) can be used to determine levels of death literacy across multiple contexts, including at a community/population level, and to evaluate the outcome of public health interventions.

The 29-item measure includes the following subscales; Practical Knowledge (8 items) including the (i) 'Talking Support' subscale (4 items) and (ii) 'Doing hands on care' subscale (4 items), 2. Experiential Knowledge (5 items), 3. Factual Knowledge (7 items) and 4. Community Knowledge (9 items) including (i) 'Accessing Help' subscale (5 items) and (ii) 'Support Groups' subscale (4 items).

This study[1] validated the measure, so that it can be used within the UK. The research includes a representative UK sample of n=399 (according to age, gender & ethnicity within Census), including participants from N.I. Data was collected in late 2020.

Findings show;

- The DLI (with one amendment) can be used to benchmark levels of death literacy at a population level within the UK
- Participants scored at the mid-point across the subscales, suggesting an opportunity for improving all aspects of death literacy for adults across the UK
- There was little socio-demographic variation in death literacy scores, evidencing the need for a life-course approach to increasing death literacy

Some key recommendations within this paper include:

- The weakest areas of death literacy to strengthen at a UK population level are around 'Factual Knowledge' and Accessing Help'
    - Factual Knowledge refers to people's knowledge about the death system, particularly information needed to plan well for dying, caregiving and death. This includes access to palliative care, completing EOL documents and funeral plans, and decision making related to dying at home, and body disposal
    - Accessing Help refers to knowing where to access equipment, physical and emotional support, that exists within the community

[1] **Graham-Wisener, L., Toner, P., Leonard, R., & Groarke, J. M. (2022). Psychometric validation of the death literacy index and benchmarking of death literacy level in a representative uk population sample. *BMC palliative care*, *21*(1), 145.**

Understanding aspects of death literacy in NI

A second research study, summarised in the report *Creating a Death Literate Socie*ty[2], was conducted in 2021 in partnership between QUB, Cardiff University and Marie Curie. We analysed a subset of the data which pertains to 506 adults in NI to understand different aspects of death literacy.

Findings show;

- Less than 50% of people in Northern Ireland were familiar with over half (8 out of 15) of key palliative and end-of-life care terms. Less familiarity with specialist terms like 'artificial hydration' and 'life sustaining treatment' was to be expected, but more than one in five people were not familiar with more common terminology like 'palliative', 'end of life' and 'hospice care'
- 73% of people were unfamiliar with the term 'advance care planning'
- 23% of people in Northern Ireland said they were uncomfortable talking about death and dying with their friends and family- this was 5% higher than the UK average and between 5-7% higher than each individual jurisdiction
- 30% of people in Northern Ireland don't know where to find information on advance care planning.
- Over half (55%) of respondents either answered strongly disagree, disagree or don't know to the statement 'I know where to find information on how to plan in advance for my care at the end of life'
- Similarly, 40% of respondents either answered strongly disagree, disagree or don't know to the statement ''if someone close to me were to die, I know where to find support'

Some key recommendations within this report include;

- That the DoH should commission an action plan for promoting death literacy across NI, with funding attached. Development of the action plan would ideally be a dedicated workstream under a new palliative care strategy for NI.

- Death education programmes should be included in relevant parts of the school curriculum in NI, as part of a life-course approach to teaching children and young people about death, dying and grief
- Courses on promoting death literacy among patients and families should be part of training and continuing professional development for relevant health and social care disciplines
- A benchmarking exercise should be carried out to assess the accessibility and quality of information materials on core death literacy issues in every statutory health and social care setting in Northern Ireland
- A representative annual survey should be carried out to measure progress and monitor trends on death literacy levels among the Northern Ireland population

[2] **Marie Curie (2022). Creating a Death Literate Society: The importance of boosting understanding and awareness of death, dying and bereavement in Northern Ireland**

Public attitudes to death talk and advance care planning in NI

Advance care planning (an aspect of death literacy) is acknowledged to be a continuous process across the life course, as recognised within the *Advance Care Planning: For Now and For the Future* policy.

Aligned to the importance of upstreaming and normalising death talk and advance care planning conversations across the population, this research study[3] examined barriers and facilitators to talking about death and dying. The study was conducted in 2021, with 381 adults in NI.

Findings show;

- Barriers to talking about death and dying included people feeling they lacked the skill to sensitively navigate these conversations, concern over becoming distressed themselves or upsetting others, and societal norms and cultural beliefs implying death should not be discussed (see below)

Theme	Subtheme	Illustrative Quotation
Apprehension at navigating conversations	Challenge of sensitively navigating conversations about death	*I don't want to sound insensitive* (Participant 249, F, 25–34 years)
	Concern over ability of others to facilitate conversations about death	*Bringing up the topic either makes others uncomfortable or dismiss it with a short "Sorry for your loss"* (Participant 847, F, 18–24 years)
Emotional responses to death talk	Conversations hindered by own emotions	*I get upset about it—don't want to make people uncomfortable* (Participant 862, F, 18–24 years)
	Perceived risk of arousing challenging emotions in others	*Fear of making others uncomfortable or upset (Participant 18, F, 35–44 years)*
Unacceptance of death talk in different social contexts	Societal norms sustain lack of integration of death talk	*It's just not done here, I am not sure why* (Participant 333, F, 35–44 years)
	Cultural beliefs can deter openness about death	*The discomfort of others regarding the topic. I am viewed as very strange for wanting to discuss "such negative topic", but it's important to me. I have a different philosophy and spirituality than those I love, which they struggle with* (Participant 398, F, 55–64 years)
	Perception that known others are unwilling to engage in death talk	*My family don't want to talk about it* (Participant 259, F, 70–74 years)
	Perception that death should only be discussed with family and close persons	*I don't like to share my personal feelings with people I am not close to* (Participant 494, F, 35–44 years)

- Facilitators to talking about death and dying included providing education along the life-course around death and dying, raising awareness of relevance across people and contexts, and healthcare professionals modelling communication (see below)

Theme	Subtheme	Illustrative Quotation
Increasing knowledge of the 'death system'	Improving information provision	*Provide more information to patients and families on their rights and choices to help guide conversations so that people can decide and opt for what is best for them/what they want (Participant 36, F, 18–24 years)*
	Education along the life course	*Firstly being taught in schools. We learn about birth but not about death.... it's still treated like a taboo subject and as a result nobody is prepared for it.. (Participant 305, F, 35–44 years)*
	Experts sharing their experience	*Using similar campaigns which raised awareness of other social issues in the past. Also finding people who are willing to share stories and the facts....carers and the professionals (Participant 82, F, 55–64 years)*
Improving interpersonal communication	Accessible communication from healthcare providers	*Health professionals be more direct when talking about death to paitents and families (Participant 324, F, 45–54 years)*
	Practical support to improve interpersonal communication skills	*Not sure, people don't know what to say. Too much emphasis on being positive when terminally ill (Participant 119, F, 45–54 years)*
	Increasing awareness of different belief systems	*Make it less medical so target the whole population on neutral footing. Ie not based on religion or beliefs but person centred and individual (Participant 32, F, 25–34 years)*
	Acknowledging individual responsibility in initiating discussions	*By each person talking to families and friends about their own feelings/wishes about dying AND (harder to do I think) asking others what their views/feelings/wishes are regarding their demise- not in general—specifically about their own case (Participant 474, F, 55–64 years)*
Encouraging acceptance of the need for death talk	Raising awareness of relevance across people and contexts	*Change attitudes by advertising how easy it can be and the benefit it is when we all know what is to happen at the end of life (Participant 71, F, 55–64 years)*
	Addressing fear surrounding discussion of death and dying	*By encouraging people to talk about their experience, take away the superstition that it's bad luck to talk about death! (Participant 158, F, 35–44 years)*
	Normalising death as a part of life	*If the topic is introduced in schools, with death being treated as a natural part of our lifecycle, a lot of the barriers and fears can be overcome (Participant 42, F, 55–64 years)*
Groups and Individuals with ability to promote the discussion		*More awareness, news programmes, newspaper articles, social media etc. (Participant 6, F, 65–69 years)*

- The barriers and facilitators identified were mapped on to behaviour change theory, suggesting that behaviour change is a useful framework from which to approach supporting the population in NI to engage with advance care planning (this was later integrated into the regional policy)

Some key recommendations within this paper include:

- The study identifies several barriers and facilitators to talking about death and dying, which map to the majority of the behaviour change (COM-B and TDF) components. This suggests that in attempting to encourage community-dwelling adults to change their behaviour towards engaging more in death talk, it is likely that multiple complex interventions are needed, supported by policy level directives.
- Interventions rooted in behavioural economics can be applied to public health policy and population-level programmes, and typically focus on restructuring social and physical environments to *gently* endorse (or 'nudge') health-promoting behaviour. Interventions based on this approach target drivers of behaviour such as emotions and impulses, habits, and social norms *indirectly*. Behavioural economics therefore presents a potentially powerful toolkit to influence decision-making around communication about death and dying by redesigning the choice architecture.

[3] **Graham-Wisener, L., Nelson, A., Byrne, A., Islam, I., Harrison, C., Geddis, J., & Berry, E. (2022). Understanding public attitudes to death talk and advance care planning in Northern Ireland using health behaviour change theory: a qualitative study. *BMC Public Health*, *22*(1), 906.**

ACCESS TO SERVICES

Compassionate Communities

Compassionate communities are a key mechanism through which death literacy is developed and mobilised. Compassionate communities empower people to support one another through serious illness, dying, death, and grief, recognising these as shared human experiences rather than solely the responsibility of health and social care. Compassionate communities complement, rather than replace, formal services by fostering local networks of care and compassion. Investment in fostering a compassionate communities approach can help to lessen demand on services by reforming the model of care, and can also help to address inequalities in access to palliative care.

Internationally, there is evidence of cost-savings to the health service from compassionate communities initiatives, where initiatives have demonstrated a reduction in unplanned admissions to hospital and fewer unscheduled visits to primary care and other allied health services (e.g. Librada-Flores et al, 2020).

I have attached a position paper, due to be launched publicly on 14th January 2025. This position paper is based on outcomes from the Inaugural Compassionate Communities in Palliative and End of Life Care Conference (9th September 2024, Canal Court Hotel Newry) alongside expert stakeholder consultation. There were 120 conference attendees representing various sectors, as well as members of the public and individuals with lived experience of caregiving, dying, death and grief. Participants came from across the island of Ireland.

Recommendations within this paper include;

In the position paper, we emphasise that caregiving, dying, death and grieving should not be the responsibility of health and society care. As such, it is our position that a clear mandate for fostering compassionate communities is needed from local government, with the below recommendations translated into specific actions and delivered through relevant government departments. There is also an emphasis on cross-border collaboration, where there has already been commitment in the new ROI adult palliative care policy to develop a compassionate communities model of care.

The below recommendations are grounded in the principle that people with lived experience and communities themselves must be at the heart of delivering on all initiatives.

1. Advocate for the adoption and implementation of this paper's recommendations by engaging with local government, government departments, councils and civic leaders

2. Support/establish an organisation with secured funding for at least five years to provide strategic leadership and act as a knowledge broker for compassionate communities across the island of Ireland

3. Deliver public awareness campaigns around the concept and benefits of compassionate communities, linked to providing recognition and reward to existing initiatives

4. Commission and complete an asset-mapping exercise to identify compassionate communities initiatives and community groups with potential to deliver initiatives across the island of Ireland. The results should be published in a publicly accessible online map and updated every six months

5. Facilitate engagement workshops in communities across the island of Ireland, to identify local need and establish partnership working between communities and health and social care.

6. Provide seed funding and mentorship for community groups to work in partnership with health and social care, to develop, deliver and evaluate impact of localised compassionate communities initiatives

7. Support the development of compassionate communities of practice, to share and to mobilise learning from existing compassionate communities initiatives

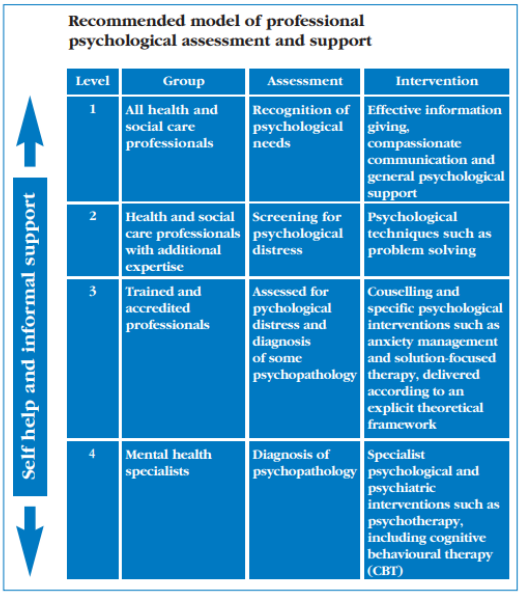
8. Establish steering groups for the development and delivery of compassionate civic charters in council areas both North/South

9. Commission research to support a 'roadmap' for fostering compassionate communities across the island of Ireland, focused on understanding local need, understanding what has worked for whom, where, and in what circumstances, and embedding best practice internationally

ACCESS TO SERVICES

Access to specialist psychological support

Clinical guidelines (NICE 2004;2008) recommend a stepped model of psychological support, with individuals with life-limiting illness and their families provided with the level of support which best meets their needs. Mental health specialists (i.e. psychologists) are referred to in clinical guidelines as having the requisite training and competencies to support individuals with more complex needs (e.g. psychiatric or mood disorders, such as anxiety or depression). Evidence-based intervention from psychologists can help alleviate distress, where it does increase in severity and complexity. There is an increased risk of severe and complex distress with life-limiting illness. The management of psychosocial aspects of care (e.g. anxiety, pain, fatigue) are a priority for patients and family carers (e.g. James Lind Alliance), particularly as people live longer with life-limiting illness.



NICE Guidance; Improving Supportive and Palliative Care for Adults with Cancer

As well as evidencing the benefit of specialist psychology input for individual patient/family support, a recent systematic review evidences the important position psychologists have in supporting and training staff- who are non-mental health professionals – in providing the best possible care. Psychologists operate at the highest level in the NICE framework for psychological support, and therefore have a key leadership role in enhancing psychological care at all levels.

Although it is acknowledged that the burden and complexity of psychological illness is high in palliative care settings (as further evidenced below with NI data), the psychology workforce in specialist and generalist palliative care in NI is significantly lacking. To illustrate, in the UK, 20 per cent of hospices have no direct access to psychologists (McInnerney et al, 2021). This rises to 100 per cent of hospices in NI with no direct access to psychologists. Specialist palliative care services are required to defer patients to primary care or to community mental health services for psychological assessment and intervention. This results in fragmented patient care, or no psychology input at all. Unsurprisingly, hospices in NI are more likely than hospices in England and Scotland to report that overall care is not at all adequate (McInnerney et al, 2021).

The inadequacy of specialist psychological support, in contravention with NICE clinical guidelines, is mirrored across generalist palliative care. For example, with the under-resourcing of psychological services within oncology. Psychological services within the HSC Trusts are not resourced adequately to allow psychologists to sit on oncology multidisciplinary teams in order to see patients at an earlier stage in their journey, or for the public to benefit from their contribution to workforce development through providing consultation, supervision and education to non-mental health specialist colleagues.

There are long waiting lists for psychological services across care settings. This is particularly impactful for individuals with advanced illness, who are not able to receive timely support and support in their place of care. The NI Cancer Strategy (2022-2032) recognises that '*it is essential that people who are receiving palliative care are seen before they become too fatigued or unwell, to be able to engage in psychological assessment or therapy*'.

Historically, there has been a lack of core funding for psychologists within specialist and generalist palliative care. Psychology staffing needs to be addressed as part of workforce planning for palliative care services in order to align with identified patient/family carer priorities, international guidelines, evidenced-based care, and therefore best practice. The new ROI adult palliative care policy has taken its lead from international guidance and provides a recommended WTE of psychology staffing per population. In NI, we are already starting from a position where even our specialist palliative care services are under-resourced compared to both the UK and ROI. For example, Our Lady's Hospice (Dublin) has staffed a psychology service for a number of years. I would recommend we urgently consider core funded psychology staffing for palliative care services in NI, in line with WTE per population recommendations as integrated into ROI and international policies.

Nature and level of psychological distress in NI

We know that the majority of individuals with life-limiting illness referred to specialist palliative care have unmet psychological needs. A research study we conducted in 2020[4], involved a case note review of referrals to five hospices (including one in NI). Documentation relating to 239 new patient referrals to hospice was reviewed; and focus groups involving 22 healthcare professionals conducted.

Findings show:

- Most patients had two or more needs documented on referral (96%). Psychological needs were recorded for the majority of patients (59%).
- Psychological needs were often not specified in detail within the referral

Some key recommendations within this paper:

- The frequency with which psychological needs are reported as a reason for referral to specialist palliative care would indicate a need for greater psychology resource and training/education within generalist palliative care
- Greater consideration of how non-physical needs of patients is detailed is warranted, within referral to specialist palliative care. The use of standardised screening tools and performance measures (e.g. the Distress Thermometer) as a supplement to free-text information, could provide greater clarity and enable hospices to individualise services and best meet patient needs

[4] **Finucane, A. M., Swenson, C., MacArtney, J. I., Perry, R., Lamberton, H., Hetherington, L., ... & Carduff, E. (2021). What makes palliative care needs "complex"? A multisite sequential explanatory mixed methods study of patients referred for specialist palliative care. BMC palliative care, 20, 1-11.**

I led the British Psychological Society response to the NI Cancer Strategy consultation, where we emphasised the need for the development of evidenced-based pathways to screen, assess and manage psychological distress. The consequence of the absence of evidence-based pathways is that clinically significant distress is under-recognised and therefore, undermanaged. It is also likely that what little psychology resource there is, may not be properly protected for those who need it most.

Several years ago, we conducted a research study [5] to validate a one-item distress screening tool (the 'Distress Thermometer' for use with individuals receiving specialist palliative care in the UK. This is a freely available tool, which is quick to administer and is one of the most widely used distress screening measures internationally. Individuals are asked to report how much distress they have experienced in the previous week, on a scale from 1-10. This research study was a collaboration between QUB and Marie Curie Hospice Belfast. We administered the one-item distress screening tool to 139 patients (admitted to inpatient unit or attending day hospice), alongside a longer distress screening tool.

Findings show;

- The number of individuals with advanced cancer experiencing clinically significant levels of anxiety, depression and overall distress according were 79/139 (43%), 86/139 (62%) and 87/139 (63%), respectively.
- Accuracy of the Distress Thermometer in screening for indicative psychological morbidity is fair to good in relation to sensitivity, but poor in relation to specificity with a number of false positives.

Some key recommendations within this paper:

- A sizeable proportion of individuals with advanced cancer receiving specialist palliative care experience clinically significant levels of anxiety, depression and distress, which would warrant further assessment and specialist psychological support. This specialist support is currently absent, with appropriate resourcing of psychology WTE per population required
- The Distress Thermometer performs adequately compared to a longer distress screening tool, and could be embedded in routine clinical practice with a cut-off of ≥5 indicating the need for further assessment and referral. This is a key tool for integration within an evidenced-base pathway to screen, assess and manage distress.

[5] **Graham-Wisener, L., Dempster, M., Sadler, A., McCann, L., & McCorry, N. K. (2021). Validation of the Distress Thermometer in patients with advanced cancer receiving specialist palliative care in a hospice setting. *Palliative Medicine*, *35*(1), 120-129.**

Finucane et al. BMC Palliative Care (2021) 20:18
https://doi.org/10.1186/s12904-020-00700-3

BMC Palliative Care

RESEARCH ARTICLE Open Access

What makes palliative care needs "complex"? A multisite sequential explanatory mixed methods study of patients referred for specialist palliative care

Anne M. Finucane[1,2*], Connie Swenson[1], John I. MacArtney[3,4], Rachel Perry[4], Hazel Lamberton[5], Lucy Hetherington[6], Lisa Graham-Wisener[7], Scott A. Murray[2] and Emma Carduff[6]

Abstract

Background: Specialist palliative care (SPC) providers tend to use the term 'complex' to refer to the needs of patients who require SPC. However, little is known about complex needs on first referral to a SPC service. We examined which needs are present and sought the perspectives of healthcare professionals on the complexity of need on referral to a hospice service.

Methods: Multi-site sequential explanatory mixed method study consisting of a case-note review and focus groups with healthcare professionals in four UK hospices.

Results: Documentation relating to 239 new patient referrals to hospice was reviewed; and focus groups involving 22 healthcare professionals conducted. Most patients had two or more needs documented on referral (96%); and needs were recorded across two or more domains for 62%. Physical needs were recorded for 91% of patients; psychological needs were recorded for 59%. Spiritual needs were rarely documented. Referral forms were considered limited for capturing complex needs. Referrals were perceived to be influenced by the experience and confidence of the referrer and the local resource available to meet palliative care needs directly.

Conclusions: Complexity was hard to detail or to objectively define on referral documentation alone. It appeared to be a term used to describe patients whom primary or secondary care providers felt needed SPC knowledge or support to meet their needs. Hospices need to provide greater clarity regarding who should be referred, when and for what purpose. Education and training in palliative care for primary care nurses and doctors and hospital clinicians could reduce the need for referral and help ensure that hospices are available to those most in need of SPC input.

* Correspondence: anne.finucane@mariecurie.org.uk
[1]Marie Curie Hospice Edinburgh, 45 Frogston Road West, Edinburgh EH10 7DR, UK
[2]Primary Palliative Care Research Group, Usher Institute, University of Edinburgh, Teviot Place, Edinburgh EH8 9AG, UK
Full list of author information is available at the end of the article

Background

People with advanced illness should be referred to specialist palliative care (SPC) services if they have needs that cannot be addressed by usual care. Criteria for specialist palliative care referral include a diagnosis of advanced cancer, physical symptoms, low performance status, psychosocial distress, advance care planning needs, family concerns and patient request [1]. However a consensus on referral criteria is lacking, and access to specialist palliative care is determined by the existence of any of these criteria, rather than the level of complexity of need [2–4].

In the United Kingdom, palliative care is provided through both specialist and generalist services. Specialist palliative care services are those offered by multidisciplinary National Health Service (NHS) teams or hospices employing staff with the requisite qualifications and expertise to support terminally ill people and their families. Most inpatient and community specialist palliative care is provided by hospices [5, 6], which are charity-based localised services funded mainly through charitable donations [7]. Hospices offer a wide range of services, free-of-charge, to address the physical, psychological, social and spiritual needs of people with a terminal illness and their families. These can be inpatient, community-based or can involve attending the hospice as an outpatient or day patient. Hospices are evolving and have shifted their focus from caring for patients with cancer to the development of services for all terminally ill patients; while also seeking to offer services earlier in the illness trajectory when needed. As hospice services have developed to suit the needs of their local population and receive only partial statutory funding through local commissioning processes, there is much variability in the services offered [7–9].

The term 'complex need' is frequently used to describe the needs of patients accessing specialist palliative care, including hospice care. There is no standard definition of complexity in palliative care, nor a distinct set of needs that are understood as 'complex' [4, 10]. Rather, qualitative studies have identified potential indictors of complex needs, including number, severity and changing nature of need, alongside the interaction of multiple needs across different domains (physical, psychological, social and spiritual) [4, 10, 11]. Communication challenges, learning disabilities and multimorbidity may increase the complexity of need [11].

At a broader systems level, dissonance in relationships between the patient, their family and/or healthcare professionals can impact complexity [4, 11]. Lack of engagement with services, sometimes as a result of potentially stigmatising pre-existing mental health issues or diseases, increase 'invisible' complexity [4]. Lack of confidence amongst some primary care professionals in caring for patients approaching end-of-life can lead to judgements that care needs are complex, whereas professionals with more experience might not consider such needs complex, highlighting the subjective nature in making judgements about complexity of need [11].

Researching complexity-informed approaches needs to account for the dynamic contexts, unpredictable process, and self-organizing objects (such as continuous adaptations initiated by frontline staff to allow them to complete tasks, given local demands), that disrupt the linear pathways of traditional medical care and research [12, 13]. As a practice-based starting point to inform our understanding of complex needs in the ecology of hospice referral processes, and to inform the development of guidance, we sought to describe the documented needs of patients referred by primary and secondary care professionals to a hospice service. As referrals of complex needs are emergent and dynamic "events in systems", [14] we then looked to explore staff perspectives on this process.

Methods

Design

We conducted a mixed methods study consisting of a retrospective case note review and qualitative data collection via focus groups. We adopted an explanatory sequential mixed methods design. This type of mixed methods design occurs in two distinct phases, starting with the collection and analysis of quantitative data, followed by the collection and analyses of qualitative data to expand on quantitative results collected in the first phase [15].

Setting

Data were collected in four hospices across three UK nations – Scotland (2 sites), Northern Ireland (1 site), and England (1 site). All offered hospice inpatient services and day therapies; three offered community palliative care Clinical Nurse Specialist (CNS) services (Hospices 1, 2 and 4); and two offered outpatient clinics (Hospices 2 and 4). There was variability in how services were organized within each hospice. For instance, in one hospice, day therapies were part of the overall community nursing service, whereas in others day therapies was a separate service. The interventions offered within day therapies also varied as has been described elsewhere [8].

Retrospective case note review

Participants

An automated list of all consecutive new referrals between June and December 2017 was generated at each hospice. All referrals were eligible for inclusion unless the referral forms and related correspondence was

missing or incomplete. A sample of approximately 240 was deemed feasible and appropriate to allow descriptive analysis across sites, in line with previous studies [16].

Data collection

We reviewed referral documentation, including referral forms and documented phone or written correspondence with the referrer, which occurred prior to contact with the patient. The format of referral forms varied across settings. Data from referral documentation were abstracted using a standardised form, developed specifically for this study, which listed indicators of complex need identified from the research literature (Supplementary material 1). Four clinicians (CS, RP, LH, HL) with experience of local referral processes undertook data collection and abstraction at their respective site (target of approximately 60 records at each site). Training in data abstraction was provided by CS and regular discussion with the wider team ensured consistency across sites. Data were abstracted directly from the referral documentation to the standardised form and recorded in Microsoft Excel. To ensure the quality of data, we implemented the strategies proposed by Gilbert et al. [17] for case note review: training of data abstractors, explicit case selection, precise definition of variables, use of standardised abstraction forms, routine meetings to review progress, and monitoring performance of data abstractors. It was not possible to blind abstractors to the aim of the study; nor for inter-rater agreement to be tested on all data collected due to resource constraints which allowed for only one abstractor per site. However, this was done on a subset where ambiguity existed.

Variables

Key variables included whether the referral form documented physical needs (e.g. pain, shortness of breath, confusion, fatigue); psychological needs, spiritual needs, functional care needs, social care needs, planning and end of life care or communication needs (Yes/No). We also extracted data on patient characteristics, primary diagnosis, source of referral and service first referred to.

Bias

To minimize the risk of selection bias, random numbers were assigned to each referral and the first 60 referrals, in numeric order, were analysed at each site. Referrals containing too few data for analyses were excluded. Measurement bias was managed by selecting data abstractors at three sites who were separate to those involved in data analysis.

Data analysis

Data were analyzed descriptively using EXCEL and SPSS version 24. Variables were compared across all sites.

Focus groups

Participants

We conducted four focus groups – one at each site. A purposive sample of staff from each hospice was invited to participate, to include representatives from the medical, nursing, allied health professional and administration teams. All received a participant information sheet and signed a consent form in advance of participation.

Data collection

A member of the research team (CS; LGW; JM; LH) with qualitative research training facilitated the focus group at each site. Two facilitators were hospice doctors working at the focus group sites (CS and LH). Two were academic researchers known to participants (LGW and JM). During each focus group, the facilitator presented key findings from the case note review (e.g. source of referrals, number and type of needs documented on referral forms) and facilitated the discussion using a semi-structured interview schedule (Supplementary material 2). Focus groups lasted 1 to 1.5 h, were audio-recorded and transcribed.

Data analysis

Transcriptions were analysed using a constant comparison approach by one member of the research team (JM) [18], reviewed by three others (AF, CS, RP) and then verified by the wider team. The research team agreed the data contained sufficient "information power" - which takes into account (a) the aim of the study, (b) sample specificity, (c) the evolving nature of complexity science and theory to which the study will contribute, (d) the descriptively rich quality of dialogue, and (e) analysis strategy – for the purposes of this study [19].

Public and patient involvement (PPI)

A member of the Marie Curie Voices group, a group of patient and carer representatives with experience of palliative care, provided feedback on the findings, which in turn informed the discussion.

Ethical and governance considerations

The South East Scotland Research Ethics Committee confirmed that this study was a service evaluation as opposed to research study, and thus external ethics approval was not required. We obtained approval from the Research Governance Committee at each hospice site. The study is reported according the Good Reporting of a Mixed Methods Study (GRAMMS) reporting guidance for mixed method studies (Supplementary material 3) [20].

Results

Retrospective case note review

Documentation for 239 referrals across four hospice sites was examined (49% female; 51% male). Mean age of

patients was 72 years (range: 22–97 years) and the majority had a primary diagnosis of cancer (87%).

Source of referral varied by hospice (Table 1). Across all hospices, most referrals came from hospital, with a third coming from general hospital teams ($n = 78$, 33%), and just under a third from hospital SPC teams ($n = 70$, 29%). Just under a third were from GPs ($n = 71$, 30%). New referrals were most frequently received by the community clinical nurse specialist (CNS) hospice team where such a service existed (56% of all referrals). 23% of all new referrals were for the inpatient unit and 19% for day services. Hospice 3 did not run a community specialist palliative care CNS service, so most referrals were for day therapies. At Hospice 1, day therapies are provided by the community team, so most referrals were initially directed there. Across all hospices, 89% of all referrals were accepted. Largely, a referral was not accepted because the patient declined the service or died prior to assessment.

Patient needs documented at the time of referral

Overall, 230 patients (96%) had two or more needs documented on referral (Fig. 1). This included 59% who had six or more distinct needs documented. For 149 (62%) of patients, needs were documented across two or more broad domains of need – physical, social, psychological, or spiritual (Fig. 2). Eight patients were referred with needs considered separate from the four domains (e.g. end of life care or functional care needs).

Physical needs were nearly always documented (Fig. 3). Pain was most frequent ($n = 144$, 60%) followed by fatigue ($n = 85$, 36%) (Fig. 4). Complex pain was specifically mentioned for 57 patients (24%). Psychological needs were noted for 140 patients (59%) but were not generally specified further. Social needs were documented on 50 referral forms ($n = 21$%), and included needs associated with caring responsibilities ($n = 20$), social isolation ($n = 15$) and housing concerns (n = 8). Spiritual needs were noted in only 8% of referral forms. Other needs documented included: rapidly changing needs (67%); family or carer support needs (52%) and functional care needs (44%) (Fig. 5).

Variation in documentation of needs by site

Across all locations, the same overall patterns existed, with physical needs most often documented, followed by psychological, social and spiritual needs in that order. However, variation was also evident (Fig. 3). Most notably, psychological needs were documented on referral for 37% of patients referred to Hospice 2, but 75% of patients referred to Hospice 3. Overall, spiritual needs were documented for 8% of all newly referred patients, but this varied from 0% in Hospice 1 to 21% in Hospice 2.

Qualitative findings

Twenty-two participants took part in focus groups across the four sites (Table 2).

Table 1 Overview of patient referrals by hospice site

Hospice	Number of referrals analysed	Source of referral[a]	Hospice service referred to	Cancer as primary diagnosis %	Male %	Female %	Age Mean (range)
1	60	48% Hospital 42% GP 5% Hospital SPC 5% Hospital and GP	83% Community 15% Inpatient 2% Day therapies	88%	48%	52%	72 (48–93 yrs)
2	62	39% Hospital 29% GP 31% Hospital SPC 2% Hospital SPC and GP	89% Community 10% Inpatient 2% Day therapies	90%	55%	45%	74 (37–93 yrs)
3	60	5% Hospital 20% GP 57% Hospital SPC 18% Community SPC	0% Community 48% Inpatient 52% Day therapies	95%	48%	52%	69 (30–94 yrs)
4	57	39% Hospital 28% GP 25% Hospital SPC 2% Hospital SPC & GP 2% Community SPC 5% Hospital and GP	51% Community 21% Inpatient 21% Day therapies 7% Unknown	74%	54%	46%	74 (22–97 yrs)
All sites combined	**239**	**33% Hospital 30% GP 29% Hospital SPC 1% Hospital SPC & GP 5% Community SPC 3% Hospital and GP**	**56% Community 23% Inpatient 19% Day therapies 2% Unknown**	**87%**	**51%**	**49%**	**72 (22–97 yrs)**

[a]Notes: 'Hospital' excludes the hospital specialist palliative care team. Hospital SPC means referral from the hospital specialist palliative care team. Percentages may not add to 100% due to rounding

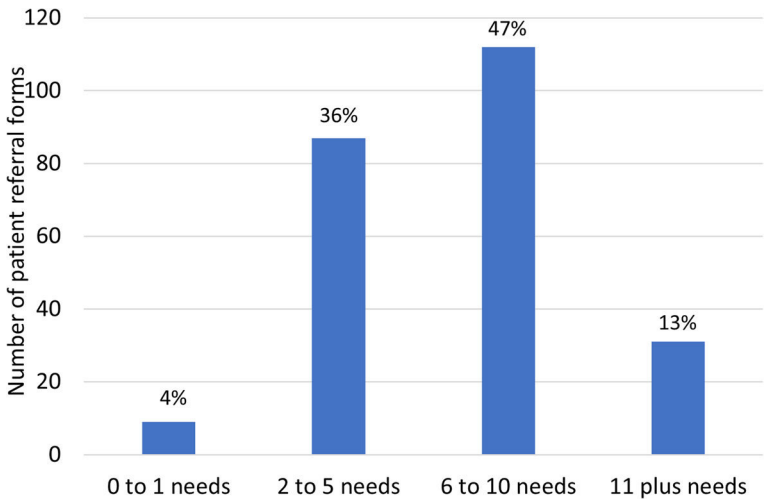


Fig. 1 Number of specific needs documented on referral forms ($n = 239$)

Six themes were identified across the focus groups: i) Prioritisation of physical needs; ii) Referral forms as limited tool; iii) Referrals associated with resource constraints, iv) Interpreting a referral form; v) Tension in accepting early versus later referrals vi) Referrals of people with cancer predominate.

Prioritization of physical needs

Participants reported that physical needs were generally prioritized on referral documentation, because these symptoms were most readily recognized, quantifiable or perceived as most likely to result in referral. Psychological, social, and other care needs were less likely to be documented.

'some doctors.. just focus on pain … and don't see the rest of the symptoms' (FG Site 1).
'often the GP, like you say, will put something down, pain, but that might not be their major problem it could be something you know social, family' (FG Site 4).
"Physical symptoms are much.. more quantifiable than maybe psychological distress or psychological symptoms or care needs.. …so that's it's easier to get across in a referral." (FG Site 2).

Referral forms as limited tools

Referral forms were perceived as limited in capturing patient needs and associated complexity. While referrals were generally perceived as appropriate – in the sense that those referred benefited from the referral - often

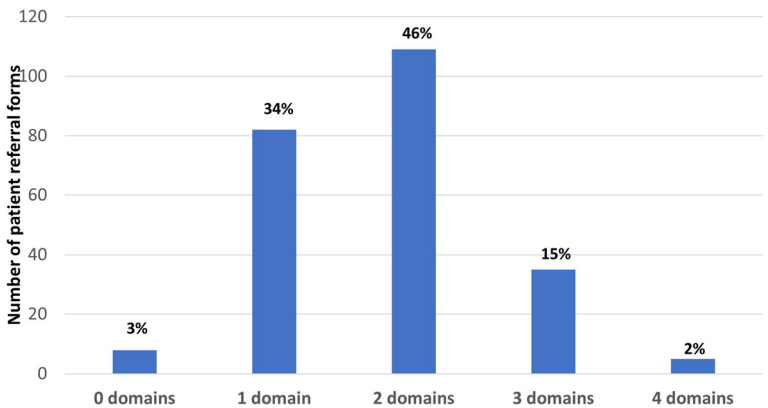


Fig. 2 Number of broad domains of need (physical, psychological, social or spiritual) documented by referrer ($n = 239$)

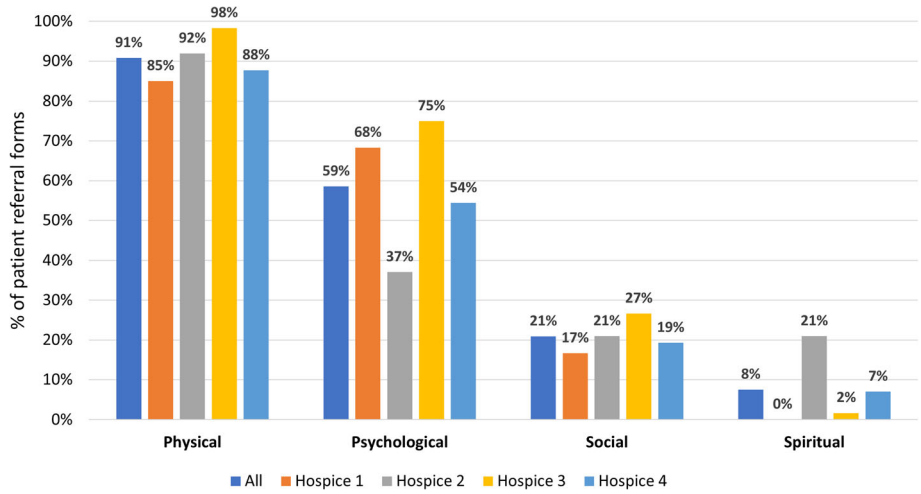


Fig. 3 Broad domains of need documented in referral documentation ($n = 239$)

the needs documented on the referral form did not align with those identified on first assessment.

> *"I think with a lot of our patients you can't capture them on paper" (FG Site 4)*

Referral forms were considered the first step to further assessment where patient's needs could be captured fully.

> *"I think because of the complexity of it, the only thing we could have done was go out and actually go on the ground and see what [the situation] was" (FG Site 2)*

> *" … when you go out it's [the referral] absolutely appropriate, but not appropriate because of the reason that the GP or any referrer thought it was appropriate for. It's because you've gone out, you've spent that time and you've uncovered a lot more than actually what was in the referral" (FG Site 1)*

Comparisons were made between different referral forms used, including the use of free text and tick boxes, but no consensus was reached as to which was preferred. Participants agreed that forms should capture essential information (although not what this should be), be simple to complete and not be expected to capture everything about a patient.

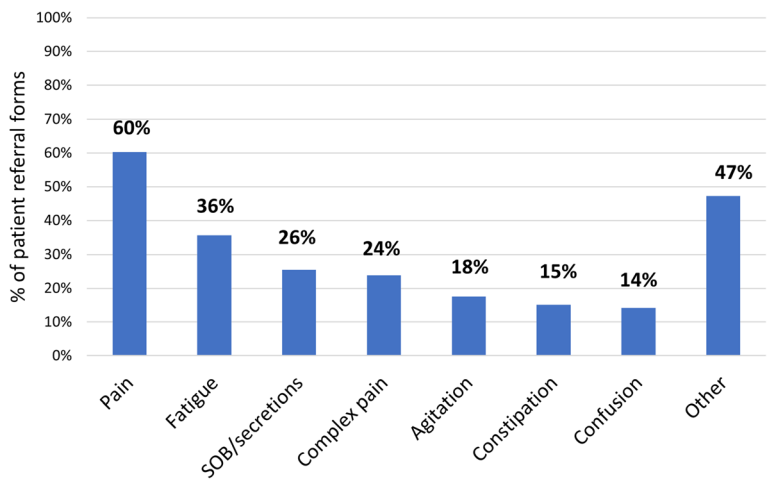


Fig. 4 Breakdown of physical needs documented by referrer ($n = 217$)

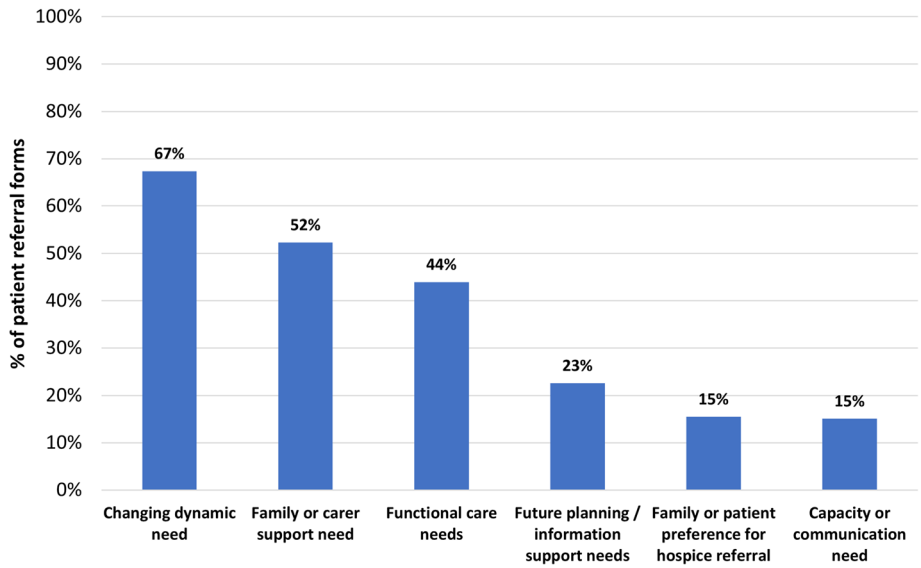


Fig. 5 Breakdown of other needs documented by referrer ($n = 239$)

"The thing I don't like about ours [referral form]..there's so many little boxes to tick and there's not enough room just for free-text. Ticking the boxes doesn't always give you what you need to know." (FG Site 3)

Referrals associated with resource constraints

Participants acknowledged the subjective nature of the judgement that a patient needs to be referred for hospice care. Sometimes this is due to a lack of resources or a referrers lack of confidence in addressing palliative care issues in their own setting:

"whatever form you use, the complexity that goes on the form will be the perception of complexity from the person writing the form … so if you've got somebody who doesn't like [palliative care], finds it really uncomfortable and doesn't want to talk about DNACPR that will probably come through on the form that actually they're [the patient] really tricky and they don't want to discuss advance care planning". (FG Site 4)

Lack of resources and time pressures locally may also result in a referral to specialist palliative care:

"…the pressures that they're [GPs] getting, I think they're under increasing demand and I think they see the specialist palliative care service as a resource." (FG Site 1)

Interpreting a referral form

Referral forms were perceived by hospice clinicians as a limited tool, of variable quality, beset by multiple tensions inherent in providing services for patients with complex needs. Thus interpreting the form became an important skill. For example, some participants reflected that the information referrers provided was influenced both by a referrer's lack of knowledge about specific hospice services *and* by a desire for the referral to be accepted.

"the referrer is trying to essentially sell you a patient so that you take them on and if they don't, you know, if they don't use the right buzzwords or use

Table 2 Focus Group Participants

Site	Total participants	Doctors	Clinical Nurse Specialist	Nurses (inpatient units)	Allied health professionals	Administrators	Medical Students
1	4	1	2	1	0	0	0
2	7	2	1	2	1	0	1
3	4	1	0	2	1	0	0
4	7	4	1	0	1	1	0
Total	**22**	**8**	**4**	**5**	**3**	**1**	**1**

the right kind of things and you know, they know that we're going to say no" (FG Site 2)

Referrers were sometimes thought to emphasise certain traits (e.g. physical symptoms) they thought would result in successful referral, as well as downplay other issues (e.g. social or family problems). Staff involved in triaging needed to decipher what service was most appropriate.

". . . that [is the] complexity of the triaging process and the skill of the triage person . . . you're triaging calls because you're getting referrals from everybody wanting beds on an inpatient unit and you're trying to prise out 'well what is it for and is it appropriate?'" (FG Site 1)

Tension in accepting early versus later referrals

Tensions were experienced when considering early referrals of patients with potentially complex needs. Participants described difficulties managing finite resources, balancing early intervention with focusing on complex needs, and the evolving expectations of hospices (e.g. to care for more people with non-malignant disease and offer specialist palliative care earlier). One tension was a recognition that hospice services could benefit most patients but was a finite resource that had to be allocated effectively.

"We still haven't worked it out [balancing resource and demand], I still don't think palliative care have worked out how we're going to manage" (FG Site 4)

Similarly, participants described the tension between prioritising more patients with complex needs and being involved with patients earlier to prevent or lessen future complexity.

"[We] advised that we come, so that we get to know you for later on down the line, which isn't a bad idea either" (FG Site 3)

Referrals of people with cancer predominate

Hospice referral is still generally perceived as appropriate for anyone with advanced cancer, irrespective of their symptoms control needs:

"I don't think it's based on need, I think it's probably a perception, still a perception, that palliative care is for people with cancer because often people are referred with cancer before they have any symptoms at all, but they've been given a diagnosis of terminal cancer." (FG Site 2).

People with a non-cancer diagnosis were perceived to be less likely to be referred, possibly as their physical symptoms tend to be managed by other services. If they are referred for specialist palliative care, this is often for psychosocial support over a longer period of time:

"I think that often the non-cancer referrals are more to do with psychological stress and carer stress and anxiety as opposed to physical symptoms" (FG Site 2).

Participants acknowledged that hospice models of care for those with advanced disease other than cancer were still developing, and presented a challenge:

" … non-malignant patients, they are normally longer-term patients so they need less intense [involvement] maybe over a period of time, so we've got to change our model and we're still struggling with that … " (FG Site 4).

Discussion

Previously described markers of complex need were evident in the referral documents of nearly all new patients referred to four hospice services. The vast majority had two or more needs documented; and for most, needs were recorded across two or more domains (physical, social, psychological, or spiritual). Changing dynamic needs were noted for over two-thirds of patients, and family or carer support needs recorded for half. However, complexity was hard to detail or objectively define based on referral documentation alone. Hospice staff perceived referral documents as limited tools, often prioritizing information on physical symptoms over other concerns. Referrals were viewed as influenced by the experience and confidence of the referrer and the resources available to them to directly meet the patients' needs and diagnosis. Referrals of those with non-malignant disease were far less frequent compared to referrals of those with cancer, and hospice models of specialist palliative care for support for this group still present challenges.

It was evident that for hospice staff, the care of patients with complex needs was intrinsic to their job but was not something easily described or understood. Although referral documentation indicated complex needs for most patients, staff perceived standardised referral forms as limited, containing information of variable quality that needed skilled interpretation to ensure patients' needs could be met. The reliability of the referrer and completeness of referral information has previously been described as a source of uncertainty or bias; and lack of knowledge or experience may over or underestimate actual palliative care need [21]. Language and lack of clear terminology is also a barrier, for instance 'dying' can indicate a person recently diagnosed with a terminal

illness, or someone approaching end of life [21, 22]. Our study found that language was sometimes used selectively to make a case for referral, whereby the referrer chose words or documented symptoms to make a stronger case for referral, and omitted others as less influential. Participants recognised the initial referral as only the start of a process, requiring further communication between the referrer and provider, culminating in the first assessment.

Physical needs were noted in 91% of referrals, and psychological needs in 59%. Physical needs were generally specified, with pain and fatigue most often documented. These symptoms are typical amongst those approaching end of life [23]; though other common symptoms such as constipation [24] appeared less frequently. Psychological symptoms were typically unspecified and lacked detail. This was because some referral forms provided structured YES/NO boxes to indicate 'psychological support'. There is a clear need to go beyond the use of generic terms such as 'psychological support' and 'emotional support' when describing psychological needs of people with a terminal illness. Specific needs relating to anxiety, depression, anger, avoidance, collusion, and anticipatory grief alongside pre-existing mental health disorders are common and should be identified to enable appropriate support. Adding the results of screening tools for psychological problems (e.g. anxiety and depression), could further improve the quality of the referral. Social needs relating to social isolation, caring responsibilities, housing concerns or 'other' were noted for one-fifth of patients newly referred; however when patient and family support needs are added, nearly two-thirds of all newly referred patients had social needs documented. Tools such as the Carer Support Needs Assessment Tool (CSNAT) can be used to identify specific carer support needs [25–27], and could enrich the quality of information on referral. Spiritual needs, in the broadest sense, were rarely documented, despite being important for patients and their families [28–31]. This may be due partly to the inclusion of an explicit section about spiritual support needs on some but not all referral form templates. Including an open section on spiritual support needs on referral forms would allow an indication of the importance of spiritual support for the terminally ill person and would help ensure that the person is directed towards the hospice service(s) most aligned with their needs. Our PPI representative noted that the term 'spiritual need' should also be defined on referral forms, so that professionals, patients and families have a shared reference point.

Resource or capacity constraints in primary or secondary care settings were perceived to influence whether a SPC referral was made – with less capacity increasing the likelihood of referral. Where there is a discrepancy between the care needs of the patient and the capacity of their care providers to meet their needs (e.g. due to lack of experience, skills or time), patient needs may increase, leading to a referral to SPC services [4, 21]. Cumulative needs [4], which we show are common amongst people with a terminal illness, can be difficult to address within the short space of time available for a primary or secondary care consultation. Lack of confidence or experience in providing palliative care support, for instance prescribing or advance care planning [32], may increase perceived complexity and referral for SPC [11].

Our study highlighted ambivalences or tensions regarding the timeliness of hospice intervention alongside dilemmas about who was best placed to assess and respond. Palliative care is an approach applicable early in the course of a life-threatening illness or severe illness [33, 34]. However, referral for SPC including hospice care tends to occur in the late stage of advanced illness [5, 35]. Staff recognised that complex needs could occur earlier, or could be prevented with earlier intervention, though the capacity implications of offering services at an earlier stage was a concern. Research shows that quality of life of people with a terminal illness oscillates over time, and for some, distress peaks on diagnosis or recurrence [36]. Models of early hospice support need to be developed and evaluated so that people can access SPC when their needs are greatest, irrespective of their prognosis.

Implications

Uncertainty around what complex needs are and ambivalence regarding the hospice services available are features of the current system. Despite this, we found that "complex needs," specifically multiple needs within and across domains, are recorded in hospice referrals, though detail is often lacking. Several steps could be taken to improve the consistency of referrals. Referrers may have a history with patients, and could draw more on this knowledge when documenting the reasons for referral to ensure that the patient and their family is directed to the service that best meets their needs. Greater consideration of the non-physical needs of patients is warranted. Across all domains, where appropriate, the use of standardised screening tools and performance measures (e.g. Karnofsky Performance Status; Phase of Illness; Distress Thermometer) as a supplement to free-text information, could provide greater clarity and enable hospices to individualize services early on. Hospices could improve the referral process by ensuring that referrers are aware of the needs addressed by each available service. Palliative care specialists could offer training and support to GPs, community nurses, care-home nurses and other staff to reach all patients in need,

especially those with non-malignant disease. Structured referral forms – now normal practice in all other specialties - could contain a section on palliative care provided prior to referral, clarifying what palliative care has already been offered, when and why the person is now being referred for hospice care.

Hospices are increasingly under pressure to show their 'worth' to commissioning groups through tangible outputs and impacts, which may contribute to a greater emphasis on more medical aspects of palliative care, which downplays the psychological, social and spiritual care provided. This may partly explain the emphasis on physical symptoms found in referral documentation. Clear communication on the interventions offered by hospices to address non-physical care needs is needed to ensure that referrers and commissioners understand the range of SPC services available, and how SPC can significantly improve quality of life for those with greatest need.

Further research is needed to develop and evaluate referral documentation that is useful and informative to both referrers and hospice service providers. We only analysed needs of those referred to hospice; future work might usefully compare the needs of those referred and those who were not referred, so that care trajectories are better understood. The ID-Pall tool has recently been developed to distinguish between needs that can be provided by non-SPC providers versus SPC [37], further validation and testing in diverse settings is now required.

Strengths and limitations

These findings relate specifically to the hospices involved in the study, and the results are not generalizable. However, this study highlights the variation in hospice service structure and the documented needs of patients referred to each hospice. The inclusion of four sites, in three regions of the UK allowed exploration of variation. Focus groups consisted of participants from hospice settings, not primary or secondary care settings, though their inclusion in future related studies is recommended.

Conclusion

Complexity was hard to detail or to objectively define based on referral documentation alone. Given increased complexity of need [38], longevity in prognosis and evidence that early interventions may ameliorate long terms problems, hospices need to provide greater clarity regarding who should be referred, when and for what reason. In the meantime, hospices can improve the referral process by specifying what hospice services are available to meet which needs; communicating regularly with referrers; and providing education and training to support referrers to meet more palliative care needs directly.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-020-00700-3.

Additional file 1.

Acknowledgements

We are very grateful to our PPI representative, Meena Bhagat, for extremely helpful comments on the results and discussion.

Authors' contributions

AMF, CS and SAM conceived of the study. AMF acted as project coordinator. CS led the early-stage planning. Data collection was undertaken by CS, JM, RP, LH, HL, LGW and EC. Analysis was conducted by AMF, JM, RP and CS, and reviewed by the wider team. The manuscript was prepared by AMF and CS, with input from JM, EC and SAM, and subsequently reviewed by the wider team. All authors reviewed and gave final approval of the version to be published.

Funding

This study was not funded by a specific grant from any funding agency in the public, commercial or not-for-profit sectors. The posts of AMF, JM, RP, HL and EC are funded by Marie Curie: www.mariecurie.org.uk. The posts of CS and LH were funded by Marie Curie during data collection period.

Availability of data and materials

Data will be made available upon request from the corresponding author.

Ethics approval and consent to participate

The South East Scotland Research Ethics Committee confirmed that this study was a service evaluation as opposed to research study, and thus external ethics approval was not required. We obtained approval from the Research Governance Committee at each hospice site. All participants received a participant information sheet and signed a consent form in advance of participation in focus groups.

Consent for publication

Not applicable.

Competing interests

AMF, CS, RP, HL, LH, and EC are employed by Marie Curie, or were employed by Marie Curie, a specialist palliative care provider with nine hospices across the UK, during the study. No other interests are declared.

Author details

[1]Marie Curie Hospice Edinburgh, 45 Frogston Road West, Edinburgh EH10 7DR, UK. [2]Primary Palliative Care Research Group, Usher Institute, University of Edinburgh, Teviot Place, Edinburgh EH8 9AG, UK. [3]Unit of Academic Primary Care, University of Warwick, Gibbert Hill, Coventry CV4 7AL, UK. [4]Marie Curie Hospice West Midlands, Marsh Lane, Solihull B91 2PQ, UK. [5]Marie Curie Hospice Belfast, 1A Kensington Road, Belfast BT5 6NF, UK. [6]Marie Curie Hospice Glasgow, 133 Balornock Rd, Glasgow G21 3US, UK. [7]Centre for Improving Health-Related Quality of Life, School of Psychology, Queen's University Belfast, Belfast BT7 1NN, UK.

Received: 22 October 2020 Accepted: 17 December 2020
Published online: 15 January 2021

References

1. Hui D, Meng Y-C, Bruera S, Geng Y, Hutchins R, Mori M, et al. Referral Criteria for Outpatient Palliative Cancer Care: A Systematic Review. Oncologist. 2016;21:895–901. https://doi.org/10.1634/theoncologist.2016-0006.
2. Mitchell H, Noble S, Finlay I, Nelson A. Defining the palliative care patient: its challenges and implications for service delivery. BMJ Support Palliat Care. 2015;5:46–52. https://doi.org/10.1136/bmjspcare-2012-000220rep.
3. Ahmed N, Bestall JE, Ahmedzai SH, Payne SA, Clark D, Noble B. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. Palliat Med. 2004; 18:525–42. https://doi.org/10.1191/0269216304pm921oa.

4. Pask S, Pinto C, Bristowe K, van Vliet L, Nicholson C, Evans CJ, et al. A framework for complexity in palliative care: a qualitative study with patients, family carers and professionals. Palliat Med. 2018;32:1078–90. https://doi.org/10.1177/0269216318757622.
5. Allsop MJ, Ziegler LE, Mulvey MR, Russell S, Taylor R, Bennett MI. Duration and determinants of hospice-based specialist palliative care: a national retrospective cohort study. Palliat Med. 2018;32:1322–33. https://doi.org/10.1177/0269216318781417.
6. National Council for Palliative Care, Public Health England,Hospice UK. National survey of patient activity data for specialist palliative care services, https://www.hospiceuk.org/docs/default-source/What-We-Offer/publications-documents-and-files/minimum-data-set-summary-report-2014-15 (2015, accessed 11 December 2020).
7. Hospice UK. What is hospice care?, https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care (2020, Accessed 11 December 2020).
8. Mitchell PM, Coast J, Myring G, Ricciardi F, Vickerstaff V, Jones L, et al. Exploring the costs, consequences and efficiency of three types of palliative care day services in the UK: a pragmatic before-and-after descriptive cohort study. BMC Palliative Care. 2020;19:1–119. https://doi.org/10.1186/s12904-020-00624-y.
9. Cox S, Murtagh FEM, Tookman A, Gage A, Sykes N, McGinn M, et al. A review of specialist palliative care provision and access across London – mapping the capital. London J Primary Care. 2017;9:33–7. https://doi.org/10.1080/17571472.2016.1256045.
10. Hodiamont F, Jünger S, Leidl R, Schildmann E, Bausewein C. Understanding complexity – the palliative care situation as a complex adaptive system. BMC Health Serv Res. 2019;19. https://doi.org/10.1186/s12913-019-3961-0.
11. Carduff E, Johnston S, Winstanley C, Moorish J, Murray S, Spiller J, et al. What does 'complex' mean in palliative care? Triangulating qualitative findings from 3 settings. BMC Palliative Care 2018; 17. https://doi.org/10.1186/s12904-017-0259-z.
12. Greenhalgh T, Papoutsi C. Studying complexity in health services research: desperately seeking an overdue paradigm shift. BMC Med. 2018;16:95. https://doi.org/10.1186/s12916-018-1089-4.
13. Greenhalgh T, Papoutsi C. Spreading and scaling up innovation and improvement. BMJ. 2019;365:l2068. https://doi.org/10.1136/bmj.l2068.
14. Hawe P, Shiell A, Riley T. Theorising interventions as events in systems. Am J Community Psychol. 2009;43:267–76. https://doi.org/10.1007/s10464-009-9229-9.
15. Creswell JW, Plano Clark VL. Designing and conducting mixed methods research. Third edition. Los Angeles: Sage Publications; 2018.
16. McIlfatrick S, Muldrew DHL, Beck E, Carduff E, Clarke M, Finucane A, et al. Examining constipation assessment and management of patients with advanced cancer receiving specialist palliative care: a multi-site retrospective case note review of clinical practice. BMC Palliative Care. 2019;18:57. https://doi.org/10.1186/s12904-019-0436-3.
17. Gilbert EH, Lowenstein SR, Koziol-Mclain J, Barta DC, Steiner J. Chart reviews in emergency medicine research: where are the methods? Ann Emerg Med. 1996;27:305–8. https://doi.org/10.1016/S0196-0644(96)70264-0.
18. Pope C, Ziebland S, Mays N. Analysing qualitative data. BMJ. 2000;320:114–6. https://doi.org/10.1136/bmj.320.7227.114.
19. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res. 2016;26:1753–60. https://doi.org/10.1177/1049732315617444.
20. O'Cathain A, Murphy E, Nicholl J. The quality of mixed methods studies in health services research. J Health Serv Res Policy. 2008;13:92–8. https://doi.org/10.1258/jhsrp.2007.007074.
21. Russell B, Sundararajan V, Hennesy-Anderson N, Collins A, Burchell J, Vogrin S, et al. Responding to urgency of need: initial qualitative stage in the development of a triage tool for use in palliative care services. Palliat Med. 2018;32:1246–54. https://doi.org/10.1177/0269216318773221.
22. Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M, Kim SH, et al. Concepts and Definitions for "Actively Dying," "End of Life," "Terminally Ill," "Terminal Care," and "Transition of Care": A Systematic Review. J Pain Symptom Manag. 2014;47:77–89. https://doi.org/10.1016/j.jpainsymman.2013.02.021.
23. Van Lancker A, Velghe A, Van Hecke A, Verbrugghe M, Van Den Noortgate N, Grypdonck M, et al. Prevalence of symptoms in older Cancer patients receiving palliative care: a systematic review and meta-analysis. J Pain Symptom Manag. 2014;47:90–104. https://doi.org/10.1016/j.jpainsymman.2013.02.016.
24. Muldrew D, Hasson F, Carduff E, Clarke M, Coast J, Graham L, et al. Assessment and management of constipation for patients receiving palliative care in specialist palliative care settings: a systematic review of the literature. Palliative Med. 2018;32:930–8. https://doi.org/10.1177/0269216317752515.
25. Aoun SM, Grande G, Howting D, Deas K, Toye C, Troeung L, et al. The impact of the Carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial. PLoS One. 2015;10. https://doi.org/10.1371/journal.pone.0123012.
26. Carduff E, Jarvis A, Highet G, Finucane A, Kendall M, Harrison N, et al. Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses:a feasibility study. BMC Fam Pract. 2016;17. https://doi.org/10.1186/s12875-016-0414-2.
27. Ewing G, Brundle C, Payne S, Grande G. The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. J Pain Symptom Manag. 2013;46:395–405. https://doi.org/10.1016/j.jpainsymman.2012.09.008.
28. Fitchett G, Murphy PE, Kim J, Gibbons JL, Cameron JR, Davis JA. Religious struggle: prevalence, correlates and mental health risks in diabetic, congestive heart failure, and oncology patients. Int J Psychiatry Med. 2004;34:179–96. https://doi.org/10.2190/UCJ9-DP4M-9C0X-835M.
29. O'Callaghan CC, Georgousopoulou E, Seah D, Clayton JM, Kissane D, Michael N. Spirituality and religiosity in a palliative medicine population: mixed-methods study. BMJ Support Palliat Care. 2020: bmjspcare-2020-002261. https://doi.org/10.1136/bmjspcare-2020-002261.
30. Cai S, Guo Q, Luo Y, Zhou Y, Abbas A, Zhou X, et al. Spiritual needs and communicating about death in nonreligious theistic families in pediatric palliative care: a qualitative study. Palliat Med. 2020;34:533–40. https://doi.org/10.1177/0269216319896747.
31. Hegarty MM, Abernethy AP, Olver I, Currow DC. Former palliative caregivers who identify that additional spiritual support would have been helpful in a population survey. Palliat Med. 2011;25:266–77. https://doi.org/10.1177/0269216310389225.
32. Howard M, Langevin J, Bernard C, Tan A, Klein D, Slaven M, et al. Primary care clinicians' confidence, willingness, participation and perceptions of roles in advance care planning discussions with patients: a multi-site survey. Fam Pract. 2020;37:219-226. https://doi.org/10.1093/fampra/cmz050.
33. World Health Organisation. Palliative Care. 2021. Available from: https://www.who.int/health-topics/palliative-care. Accessed 5 Jan 2021.
34. Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, et al. Redefining Palliative Care: a New Consensus-based Definition. J Pain Symptom Manag. https://doi.org/10.1016/j.jpainsymman.2020.04.027.
35. Mulville AK, Widick NN, Makani NS. Timely Referral to Hospice Care for Oncology Patients: A Retrospective Review. Am J Hospice Palliative Medicine. 2019;36:466–71. https://doi.org/10.1177/1049909118820494.
36. Murray SA, Kendall M, Mitchell G, Moine S, Amblàs-Novellas J, Boyd K. Palliative care from diagnosis to death. BMJ. 2017;356:j878. https://doi.org/10.1136/bmj.j878.
37. Teike Lüthi F, Bernard M, Beauverd M, Gamondi C, Ramelet A-S, Borasio GD. IDentification of patients in need of general and specialised PALLiative care (ID-PALL©): item generation, content and face validity of a new interprofessional screening instrument. BMC Palliative Care. 2020;19:19. https://doi.org/10.1186/s12904-020-0522-6.
38. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med. 2017;15:102. https://doi.org/10.1186/s12916-017-0860-2.

Publisher's Note

BMC Palliative Care

RESEARCH

Open Access

Psychometric validation of the death literacy index and benchmarking of death literacy level in a representative uk population sample

Lisa Graham-Wisener[1*], Paul Toner[1], Rosemary Leonard[2] and Jenny M. Groarke[1,3]

Abstract

Background: Death literacy includes the knowledge and skills that people need to gain access to, understand, and make informed choices about end of life and death care options. The Death Literacy Index (DLI) can be used to determine levels of death literacy across multiple contexts, including at a community/national level, and to evaluate the outcome of public health interventions. As the first measure of death literacy, the DLI has potential to significantly advance public health approaches to palliative care. The current study aimed to provide the first assessment of the psychometric properties of the DLI in the UK, alongside population-level benchmarks.

Methods: A large nationally representative sample of 399 participants, stratified by age, gender and ethnicity, were prospectively recruited via an online panel. The factor structure of the 29-item DLI was investigated using confirmatory factor analysis. Internal consistency of subscales was assessed alongside interpretability. Hypothesised associations with theoretically related/unrelated constructs were examined to assess convergent and discriminant validity. Descriptive statistics were used to provide scaled mean scores on the DLI.

Results: Confirmatory factor analysis supported the original higher-order 8 factor structure, with the best fitting model including one substituted item developed specifically for UK respondents. The subscales reported high internal consistency. Good convergent and discriminant validity was evidenced in relation to objective knowledge of the death system, death competency, actions relating to death and dying in the community and loneliness. Good known-groups validity was achieved with respondents with professional/lived experience of end-of-life care reporting higher levels of death literacy. There was little socio-demographic variability in DLI scores. Scaled population-level mean scores were near the mid-point of DLI subscale/total, with comparatively high levels of experiential knowledge and the ability to talk about death and dying.

Conclusions: Psychometric evaluations suggest the DLI is a reliable and valid measure of death literacy for use in the UK, with population level benchmarks suggesting the UK population could strengthen capacity in factual knowledge and accessing help. International validation of the DLI represents a significant advancement in outcome measurement for public health approaches to palliative care.

Pre-registration: https://osf.io/fwxkh/

*Correspondence: l.graham-wisener@qub.ac.uk

[1] Centre for Improving Health-Related Quality of Life, School of Psychology, Queen's University Belfast, Belfast BT7 1NN, UK
Full list of author information is available at the end of the article

Keywords: Death literacy, Death literacy index, Public health, Palliative care, End of life care, Carers, Community development, Death education, Validation, UK

Background

The global death rate and demand for palliative care is projected to increase substantially over the next two decades [1], with an estimated 42 per cent increase in demand for palliative care in the UK by 2040 [2]. The 'new public health approach' to end-of-life care (EoLC) is concerned with the potential for increased scarcity of statutory palliative care provision as demand rises [3], but also questions the value of a model of care focused solely on institutionalised services, underpinned by the Biomedical Model. Public health approaches such as the Health Promoting Palliative Care model or 'Compassionate Communities' [4], advocate for a shift towards a social model of EoLC, where each social actor is empowered to contribute [3]. A core principle of new public health approaches to EoLC are around fostering community participation and agency with recognition of the substantial burden of informal carers in providing EoLC and the need for entire communities rather than professional service providers to support individuals at the end-of-life [5, 6].

Extensive qualitative research with individuals with lived experience of caring for someone dying at home by researchers in Australia [7–9] suggested that over time those in informal caring networks develop skills and abilities for providing EoLC. The capacity which is developed by individuals has been termed 'death literacy' and is defined by the authors as; '*the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and death care options. People and communities with high levels of death literacy have context specific knowledge about the death system and the ability to put that knowledge into practice*' [10]. Four theoretical facets of death literacy are proposed, described as knowledge, skills, experiential learning, and social action [11].

Although there is indication of a range of community-based new public health EoLC initiatives in practice, few are formally evaluated [12] which means there is little available evidence on the impact of such an approach. One identified challenge to evaluating community-based initiatives is the lack of an outcome measure which meaningfully captures the multi-dimensional impact of 'Compassionate Communities' intervention [12]. Existing tools largely measure individual constructs such as clinical concerns or knowledge, and do not include a focus on community support [13].

The recently developed Death Literacy Index (DLI; [13]) addresses this important gap. This is a 29-item measure designed to assess levels of death literacy across multiple contexts, including at a community/national level, and to evaluate the outcome of public health interventions. The development of the DLI was informed by an existing theoretical conceptualisation of death literacy [11] and relevant measures, and was refined with input from professionals with experience in the EoLC sector. The measure has previously been validated by the original authors [10, 13] who administered the measure to 1200 participants from the general population in Australia, with analysis involving exploratory and confirmatory factor analyses. This confirmed a structure with four subscales, two of which have two subscales. The DLI subscales reported high reliability and good internal consistency. Convergent validity was evidenced between scores on the DLI and items measuring objective knowledge of the death system, end-of-life actions and attitudes, and with a measure of death competence (Coping with Death Scale; [14]). The measure has also been piloted in several Australian community samples [10], and in one UK community sample (St Nicholas Hospice).

The DLI is the first rigorously developed measure of the construct of death literacy, which is a key outcome for public health interventions in palliative care (a priority public health area). Although the measure evidences good psychometric properties in an Australian context, it has not been validated in other international contexts so it is unclear how it performs cross-culturally. The current study will provide the first international validation of the DLI, in a representative UK population sample, and a benchmark of DLI and subscale scores for the UK. If the measure performs well, this will allow UK researchers, practitioners, and policymakers to evaluate community/organisation and national level strategies and interventions to increase death literacy.

Aim

The primary aim of this study was to examine the psychometric properties of the Death Literacy Index (DLI, Version 1.0) in a UK population-level sample. The secondary aim was to provide a benchmark of DLI and subscale scores for the UK, and to examine demographic variability in scores.

The objectives were:

I. To determine the psychometric properties of the DLI in a UK population level sample, in relation to structural, construct validity, internal consistency, and interpretability
II. To provide a benchmark (scaled mean score) on the DLI and subscales in a UK population-level sample
III. To examine the demographic variability in the DLI in a UK population-level sample

Methods

Study design

A cross-sectional online survey, with validation of the Death Literacy Index informed and reported according to the COSMIN Study Design checklist for patient-reported outcome measurement instruments [15]. The study protocol was pre-registered on the Open Science Framework (https://osf.io/fwxkh/).

Population and settings

Participants were prospectively recruited via an online crowdsourcing platform managed by Prolific Academic Ltd (http://www.prolific.co). A nationally representative sample of participants representing the target population was recruited from the estimated 41,000 UK residents on the panel, stratified across age, sex and ethnicity in alignment with the proportions reported in the UK Office of National Statistics Census data [16]. Prolific establishes the population strata, with a predetermined number of open slots into which eligible participants in the panel can enrol on a first-come basis. Inclusion criteria included: adults ($\geq$ 18 years of age) currently living in the UK, and with capacity to express their opinion. Participants read a participant information sheet and provided explicit informed consent before completing the survey via Qualtrics online platform [17]. Responses were collected between 19th October and 3rd November 2020. Median completion time was approximately 10 min. A small financial incentive was offered for completion, equivalent to £9.51/hour.

Measures

Measures included the Death Literacy Index (DLI; [13]) alongside several measures to assess construct validity. Death literacy was expected to be positively associated with death competency, with the Coping with Death Scale [14] included to assess convergent validity, alongside items to assess i) objective knowledge and ii) actions regarding discussion of death and dying. A negative association was expected between death literacy and loneliness, with the Short Revised UCLA Loneliness Scale [18] included to assess discriminant validity. Lastly, information on socio-demographic characteristics were collected, including individual experiences of death, dying and loss (e.g. working, volunteering or lived experience) to assess known group validity.

The death literacy index (DLI, version 1.0; [13])

A 29-item self-report measure of the construct of death literacy, with a higher-order factor structure composed of four subscales, two of which have two subscales; 1. Practical Knowledge (8 items) including the (i) 'Talking Support' subscale (4 items) and (ii) 'Doing hands on care' subscale (4 items), 2. Experiential Knowledge (5 items), 3. Factual Knowledge (7 items) and 4. Community Knowledge (9 items) including (i) 'Accessing Help' subscale (5 items) and (ii) 'Support Groups' subscale (4 items). Responses are on a 5-point Likert scale (from 1 to 5). Subscale scores are computed by summing items and scaling per number of items in subscale (with a range of scores between 0 and 10). Emerging evidence on the psychometric properties of the DLI in a community-based population in Australia is good [13], confirming structural, cross-cultural and construct validity, internal consistency, and interpretability. The measure has also been piloted in one UK community sample (Mildenhall, England as facilitated by St Nicholas Hospice). Leonard and colleagues in correspondence confirmed that in the UK community sample there were no items which participants found difficult or omitted. The scaled mean scores on the subscales/DLI total score ranged from 4.6- 7.5 with evidence of ceiling effects, and with good internal consistency (Cronbach's alpha for the scale was 0.927 and sub-scales ranged from 0.794 to 0.904).

Coping with death scale [14]

A 30-item self-report measure of the construct of death competency. The scale assesses both one's sense of competence in handling death and concrete knowledge concerning preparation for death. Participants are instructed to indicate the extent to which they agree with 30 statements using a 7-point Likert scale. Items are summed, with a range of scores between 30 and 210. The scale has shown good internal consistency and stability with various samples, as well as some evidence of construct validity in distinguishing hospice volunteers from controls and predicting death preparation behaviours [19]. Cronbach's alpha in the current sample indicates good internal consistency (30 items, $\alpha = 0.94$).

Short revised UCLA loneliness scale [18]

A 3-item self-report measure of the construct of loneliness. The scale measures three different aspects of

loneliness, (social connectedness, relational connectedness, and self-perceived connectedness). Participants are instructed to indicate how often they feel that way with three statements, using a 3-point Likert scale (from 1 to 3). The items are summed. This is a widely used measure of loneliness, developed for large online surveys, and demonstrates good psychometric properties in relation to the full UCLA scale [20]. Good internal consistency (3 items, $\alpha = 0.86$) was reported for the current sample.

Objective knowledge items

Developed by the original DLI authors [13], this includes four items to measure the objective knowledge of the death system. An example includes 'What is palliative care?' (response options; Care received only by people in the last few weeks or days of life, Care for people aged over 85, Care that aims to improve the quality of life of people with a life-threatening illness). Participants provide categorical answers, and correct items are summed.

Actions regarding discussion of death & dying items

Developed by the original DLI authors [13], this includes two items to measure the attitudes and actions to discussion of death and dying. The items are 'In my community we discuss death and dying' and 'In my family we discuss death and dying'. Participants provide answers using a 5-point Likert scale (from 1 to 5).

Data analysis

Sample size calculation

The sample size estimation was calculated on the basis of the factor analysis. Where factor structure is known a sample size of > 200 is recommended [21]. A sample size of $n = 399$ meets multiple criteria, with some researchers recommending a sample size of at least 300 [22, 23] and others recommending participant to item ratios ranging from 5 to 10 participants per item [24], with any less than 3 participants per item deemed inadequate [25].

Ethics

Research ethics approval was provided by the Queen's University Belfast Engineering and Physical Sciences Faculty Research Ethics Committee (Reference; EPS 20_218) on 11th September 2020. The study was conducted in accordance with the Declaration of Helsinki [26] and participants completed an informed consent statement prior to completion of the survey.

Analysis

Data were exported from Qualtrics [17], and analysed using the Statistical Package for Social Science for Windows, Version 25 (SPSS Inc., Chicago, IL, USA), an alpha level of $p < 0.05$ was considered statistically significant. The ordinal responses of the DLI were treated as continuous data. There were no missing data as forced responses were used in the survey. The scaled mean of the subscales is used throughout as recommended by the measure's authors for benchmarking of population level scores, with raw scores used for assessment of interpretability.

Objective 1

The psychometric properties of the DLI were evaluated according to standard methodology as outlined by COSMIN [15, 27].

Dimensionality The validity of the factor structure identified in the original scale development study [13] was examined in the current study by confirmatory factor analysis (CFA) using Structural Equation Modelling (SEM) in Amos version 23 (SPSS Inc., Chicago, IL, USA). Preliminary analysis to confirm the suitability of the data for factor analysis included inspecting the correlation matrix for at least several moderate-strong inter-item correlations (> 0.3) and for no perfect multicollinearity (< 0.9). Sampling adequacy was also assessed by the Kaiser–Meyer–Olkin (KMO) value (threshold > 0.6) and Barlett's Test of Sphericity (significance at < 0.05). Preliminary analyses evidenced sampling adequacy for factor analysis with largely moderate inter-item correlations but no perfect multicollinearity with all inter-item correlations < 0.83. A KMO value of 0.92 and a significant Barlett's Test of Sphericity, $\chi 2\ (435) = 8150.66$, $p < 0.001$ indicated suitability for factor analysis. Variance–covariance matrix with maximum likelihood (ML) estimation procedure was used for SEM, which is appropriate if there are more than three ordinal categories [28]. Assumptions for ML include multivariate normality. The univariate normality of the variables was assessed by kurtosis and skewness values, with recommended thresholds of moderate non-normality of < 2 for kurtosis and < 8 for skewness [29]. All the univariate skewness and kurtosis values were smaller than the recommended thresholds of moderate non-normality. At the multivariate level, multivariate kurtosis = 148.37 with a significant Mardia's coefficient of 34.95, with threshold of < 5 indicating multivariate normality [30]. This suggested univariate normality and a multivariate departure from normality. The data was inspected for multivariate outliers by Mahalanobis distance value. Removing five true outliers (substantial distances from other cases) reduced the multivariate kurtosis to 127.20 and Mardia coefficient to 29.772. In all subsequent analyses, 394 participants are the focus. The initial model specified was the 29 items of the DLI, loading onto a hierarchical structure with 8 factors. A second model with a new item developed for the UK context (under Factual Knowledge scale) was tested, as specified

a priori in the study pre-registration. This item asks about the contribution of 'funeral home staff', in place of an item referring to the contribution of 'cemetery staff'.

Model fit was assessed using a series of indices, according to best practice [31]. A non-significant chi square goodness of fit test is indicative of a well-fitting model and was considered but is sensitive to sample size [28]. Additional model fit indices used are the normed chi square (Q), the comparative fit index (CFI), the root mean square of approximation (RMSEA), and the standardised root mean square residual (SRMR). Cut-offs of fit indices include; Q; acceptable criteria vary from under 2 [32] to less than 5 [33]; CFI: ≥ 0.90 and 0.95 reflect acceptable and excellent fit to the data, respectively [34]. RMSEA and SRMR; values between 0.05 and 0.09 indicating adequate model fit and values < 0.05 indicating a very good fit [35]. Modification indices available in CFA have been used to identify misspecification in the model. Decisions regarding modifications were based on theoretical in addition to psychometric considerations of item and scale content. We planned to eliminate items if they had low factor loadings (i.e., standardized regression coefficients) (< 0.40), or if modification indices suggested they had significant loadings (> 0.30) with unintended latent factors [28].

Internal consistency After determining dimensionality based on theoretical assumptions and model fit according to standard criteria outlined above, items were evaluated for their psychometric properties. This involved examining the reliability of the unidimensional subscales separately by Cronbach's alpha and coefficient omega. Item to total correlations (r > 0.30 as a minimum criterion [36]. A Cronbach's alpha coefficient between 0.70 and 0.95 indicates good internal consistency without homogeneity [37].

Construct validity Is the extent to which scores on an instrument relate to other measures (convergent validity/discriminant validity) or produce expected differences in scores between 'known' groups (known-groups validity). It is given a positive rating if at least 75% of the results are consistent with predefined hypotheses. Construct validity of the DLI was tested against items measuring people's knowledge of the death system, a measure of death competence and for respondents identifying as having professional or lived experience of death, dying and loss. Pearson's correlation coefficients or ANOVA were undertaken according to predefined hypotheses of convergent/discriminant validity. We define the strength of the correlation as strong (0.7–1.0), moderate (0.4–0.7), weak (0.2–0.4) and absent (0.0–0.2) [38]. We define the strength of the ANOVA as small (Eta sq = 0.01), medium (0.06) or large (0.14) [38].

Convergent validity H1: Moderate positive association expected between an individual's objective knowledge of the death system and the DLI and subscale scores.

H2: Moderate positive association expected between items of individual's scores on the Coping with Death Scale [14] and the DLI and subscale scores.

H3: Moderate positive association expected between items of individual's actions in relation to discussing death and dying and the DLI and subscale scores.

Known-groups validity H4: Moderate positive association expected for individuals with experience working/volunteering or with prior lived experience of death, dying and loss and the DLI and subscale scores.

Discriminant validity H5: Moderate negative associations expected between items of individual's scores on the Short Revised UCLA Loneliness Scale [18] and the DLI and subscale scores.

Interpretability Was determined by analysing the distribution of participants' total scores (median, range, interquartile range), with floor and ceiling effect indicated if 15% of respondents achieved the lowest or highest possible score, respectively.

Objectives 2 & 3: Descriptive statistics were used to provide a scaled mean score on the DLI and subscales. ANOVA were used to examine the relationship between demographic variables and DLI/subscale scores.

Results

There were 417 responses to the survey. Responses were screened for data quality including for potential duplicate responses and lack of engagement, with 18 responses removed for incomplete data or having a completion time less than half the median completion time. Responses were forced, so there were no missing data. After inspecting the included data ($n = 399$) for multivariate normality, five outliers were removed. The included sample ($n = 394$) were a mean age of 45.8 years old (SD 15.73). The majority of participants reported to not have any personal or professional end-of-life care experience ($n = 243$, 61.7%). A minority reported to have personal end-of-life care experience, considering themselves ($n = 10$, 2.5%) or a close person ($n = 37$, 9.4%) to be in the last few years of life, or reporting to have been bereaved

in the last two years ($n=67$, 17%). A minority reported to have professional end-of-life experience, either working or volunteering with people at end of life ($n=41$, 10.4%) or individuals experiencing grief or bereavement ($n=27$, 6.9%) or having attended training on helping people with dying, grief or bereavement ($n=29$, 7.4%). Table 1 shows the other medical and socio-demographic information for this sample.

Dimensionality

ML estimation method with bootstrapping was used to provide a more accurate estimation of standard errors in relation to p values and confidence intervals. The Bollen-Stine bootstrap p was used as an alternative to $\chi 2$ [39]. The bootstrapping sample was 250, with 95% confidence interval as recommended by Nevitt and Hancock [40].

The first model specified was the 29 items loading on to their 8 respective factors as per the original model reported in the initial development of the DLI [13]. This refers to 4 subscales, two of which have their own 2 subscales; 1. Practical Knowledge including the (i) 'Talking Support' subscale and (ii) 'Doing hands on care' subscale, 2. Experiential Knowledge, 3. Factual Knowledge and 4. Community Knowledge including (i) 'Accessing Help' subscale and (ii) 'Support Groups' subscale. This model was a good fit of the data; χ^2 (369) = 822.12, $p<0.001$, Bollen-Stine bootstrap $p=0.004$, Q = 2.23, CFI = 0.94, RMSEA = 0.07 (90% CI, 0.050-0.061), SRMR = 0.07. There were no items with low factor loadings (< 0.40), and no modification indices suggesting significant cross-loadings (> 0.30). A second model was specified to test whether the inclusion of a new item in the Factual Knowledge subscale ('*I know the contribution the funeral home staff can make at end of life*') impacted model fit. This replaced an original item ('*I know about the contribution the cemetery staff can make at end of life*') as it was deemed more culturally appropriate for UK respondents. There was a slight reduction in terms of the model fit for this second model but this model was still a good fit on the majority of indices; χ^2 (369) = 871.69, $p<0.001$, Bollen-Stine bootstrap $p=0.004$, Q = 2.36, CFI = 0.93, RMSEA = 0.07 (90% CI, 0.054-0.064), SRMR = 0.07. Nonetheless, the factor loading of the new item (Q24) was greater (0.71) than the original item (0.63), with the reliability and factor loading of the Factual Knowledge subscale on the death literacy latent variable remaining largely consistent. Modification indices, however, showed a degree of variance shared between the new item and another item on the same subscale ('*I know how to navigate funeral services and options*'). In a third model, the new replacement item was retained ('*I know about the contribution the cemetery staff can make at end of life*') and its error term was co-varied with the item

Table 1 Medical and socio-demographic characteristics of sample ($n=394$)

	N	%
Gender		
Male	193	49.0
Female	200	50.8
Other	1	0.3
Ethnicity		
White	313	79.4
Asian ethnic group	38	9.6
African ethnic group	19	4.8
Arab ethnic group	2	0.5
Latino or Hispanic ethnic group	2	0.5
Other	9	2.3
Mixed/multiple	11	2.8
Language spoken at home		
English	354	89.8
Mainly English	23	5.8
Other language	17	4.3
Relationship Status		
Single	87	22.1
Partnered but not living together	33	8.4
Married or living with a partner	239	60.7
Divorced	26	6.6
Separated but not divorced	5	1.3
Widowed	3	0.8
Other	1	0.3
Highest Level of Education		
Lower secondary level	48	12.2
Upper secondary level	84	21.3
Post-secondary non-tertiary general education	59	15.0
Undergraduate degree	121	30.7
Postgraduate qualification	71	18.0
Doctoral degree	7	1.8
Other	4	1.0
Employment Status		
Employed full-time	162	41.1
Employed part-time	60	15.2
Casual	11	2.8
Not working	31	7.9
Retired	57	14.5
Actively seeking work	18	4.6
Student	31	7.9
Other	24	6.1
Annual household income (pre-tax)		
< £12,500	53	13.5
£12,501 to £50,000	239	60.7
£50,001 to £150,000	96	24.4
Over £150,000	6	1.5
Dependents		
Children	208	52.8
Dependent adults	44	11.2

Table 1 (continued)

	N	%
Religious or spiritual background		
Yes	116	29.4
No	278	70.6
Belief in an afterlife		
Yes	98	24.9
No	133	33.8
I don't know or am unsure	163	41.4
Location		
Rural- isolated dwelling, hamlet or village	71	18.0
Town- small or large town	196	49.7
City	127	32.2
Chronic Health Conditions		
Chronic Physical Illness	66	16.8
Chronic Mental Illness	22	5.6
Terminal Illness	1	0.3

('*I know how to navigate funeral services and options*'). This resulted in overall model fit indices superior to the initial specified model; χ^2 (368) = 812.83, $p < 0.001$, Bollen-Stine bootstrap $p = 0.004$, Q = 0.2.21, CFI = 0.94, RMSEA = 0.07 (90% CI, 0.050-0.061), SRMR = 0.07. The path diagram for this final model is presented in Fig. 1. The final 29 items of the DLI measure validated for UK context, their beta weights (β), that is their factor loadings, as well as, the proportion of variance in the latent construct explained by that item (r^2) are reported in Table 2.

Internal consistency

The Cronbach's alpha for each subscale were between α = 0.76 and α = 0.93, with the Omega coefficient between ω = 0.78 and ω = 0.93 (see Table 2), evidencing good internal consistency without homogeneity. All item to total correlations met the minimum criteria of r > 0.30.

Construct validity

Convergent validity

Convergent validity can be evidenced with significant moderate positive associations between the subscales/DLI total score and objective knowledge of the death system, between the DLI and death competence (Coping with Death Scale; [14]), and between the DLI and actions relating to death and dying in the family and community (see Table 3) as hypothesised. Overall, more than 75% of the results are consistent with the predefined hypotheses in terms of direction of the effect (H1, H2 & H3). However, the strength of the correlation was not as expected and was weak for the subscales/DLI total score for the majority of constructs, apart from death competency where moderate correlations as hypothesised were observed.

Known groups validity

Known groups validity was assessed for individuals identifying as having professional expertise in end-of-life care or bereavement, professional training, or lived experience. Due to a low number of participants identifying as being in the last years of life ($n = 10$), this subgroup was not assessed. Table 4 shows that all roles, apart from being a carer of someone who is at the end of life, are related to higher mean scores on all the DLI subscales in comparison to individuals identifying with none of the 'expert' roles in line with hypothesised findings (H4). The eta-square statistics show that the strength of these relationships was either medium to large on the subscales, and large for the DLI total score. Individuals identifying as a carer of someone at the end of life report significantly higher levels of death literacy on the majority of subscales and the DLI total score, however all effect sizes were small.

Discriminant validity

There was a significant negative association between the majority of the DLI subscales/DLI total score and loneliness (Short Revised UCLA Loneliness Scale; [18]) (see Table 3) in line with what was predicted (H5). However, the eta-square statistics show the strength of these relationships were weak overall and not the moderate associations expected.

Interpretability

Interpretability was assessed using the individual raw data for each subscale, i.e. the item totals of participants' scores. The participant's total score on each subscale represented the total possible range for all subscales (see Table 5). There was no evidence of floor or ceiling effects on DLI total score, or the majority of subscales except for 'Factual Knowledge'. Using the criterion of > 15% of respondents achieving the lowest possible score, there is some evidence of a floor effect for this subscale.

UK population DLI benchmarks

The scaled mean scores for each of the subscales and the DLI total score is reported for the UK population (see Table 6). Individuals from the UK appear to have high levels of experiential knowledge and the ability to talk about death and dying, relative to other subscales.

Relationship between DLI and demographic variables

In relation to demographic variability in the DLI, the majority of demographic variables were either non-significant or reported weak effect sizes (see Table 7),

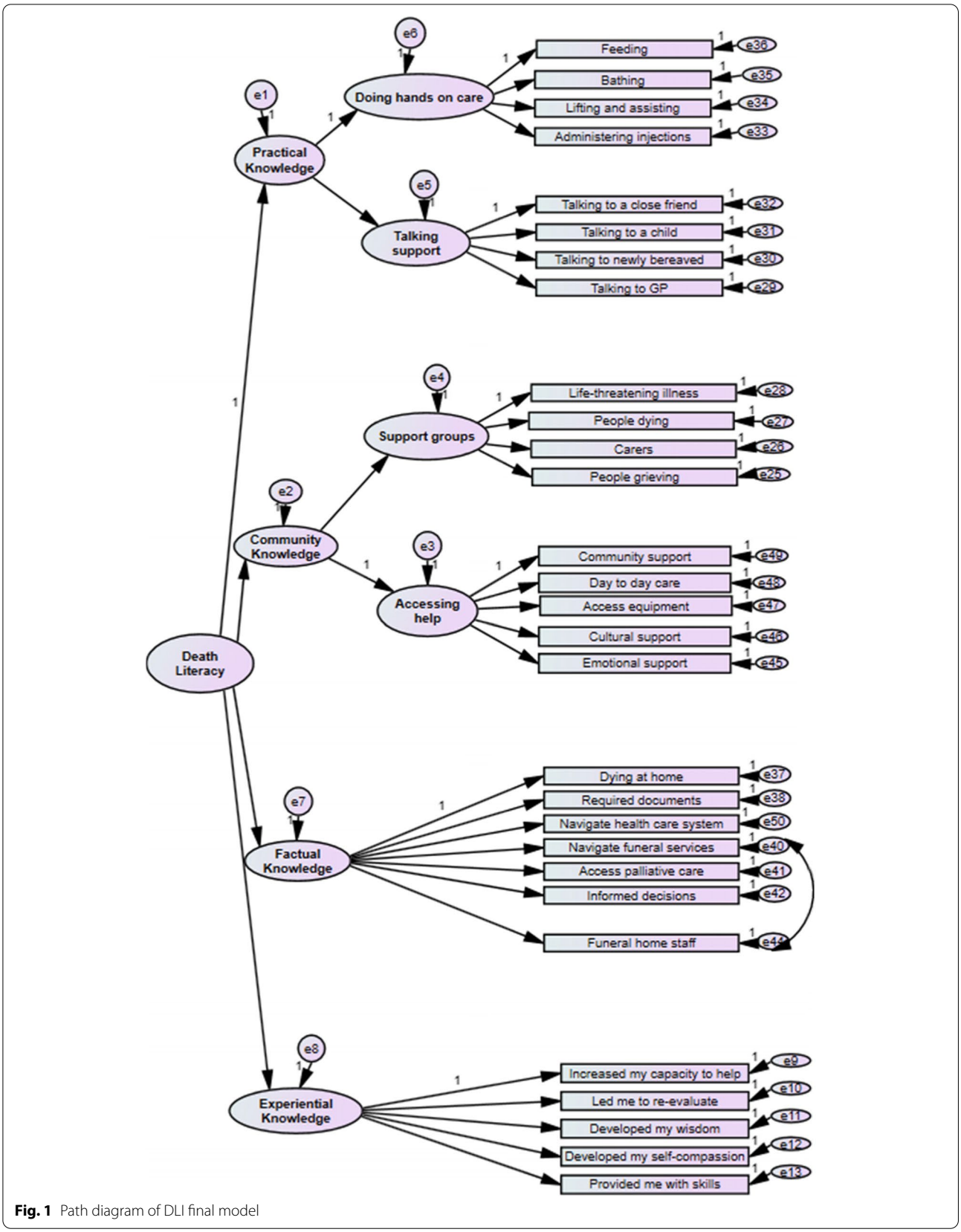


Fig. 1 Path diagram of DLI final model

Table 2 The Death Literacy Index, internal consistency, and descriptive statistics of 8 subscales, and psychometric properties of 29 final scale items

Subscales and items	β (95% CI)	*p*	r^2	α/ ω	M (SD)[1]
Practical Knowledge	0.824 (0.676, 0.949)	.020	.68	.791/.784	5.35 (1.91)
Doing hands on care	0.698 (0.595, 0.850)	.005	.49	.763/.776	4.73 (2.43)
Q1. Feeding a person or assisting them to eat	0.856 (0.807, 0.907)	.006	.73		
Q2. Bathing a person	0.848 (0.797, 0.910)	.006	.72		
Q3. Lifting a person or assisting to transfer them	0.598 (0.511, 0.680)	.008	.36		
Q4. Administering injections	0.415 (0.320, 0.517)	.005	.17		
Talking support	0.679 (0.552, 0.823)	.008	.46	.780/.784	5.96 (2.16)
Q5. Talk about death, dying or grieving to a close friend	0.705 (0.618, 0.782)	.006	.50		
Q6. Talk about death, dying or grieving to a child	0.585 (0.494, 0.675)	.011	.34		
Q7. Talk to a newly bereaved person about their loss	0.677 (0.594, 0.740)	0.12	.46		
Q8. Talk to a GP about support at home or in their place of care for a dying person	0.788 (0.714, 0.840)	.005	.61		
Community Knowledge	0.863 (0.764, 0.948)	.008	.74	.922/.922	4.48 (2.29)
Support groups	0.608 (0.514, 0.683)	.022	.37	.923/.923	5.06 (2.43)
Q9. People with life threatening illnesses	0.883 (0.843, 0.913)	.015	.78		
Q10. People who are dying	0.935 (0.903, 0.954)	.012	.87		
Q11. Carers for people who are dying	0.847 (0.790, 0.879)	.021	.72		
Q12. People who are grieving	0.801 (0.739, 0.846)	.011	.64		
Accessing help	0.965 (0.886, 1.073)	.005	.93	.927/.928	3.91 (2.77)
Q13. Access community support	0.851 (0.799, 0.885)	.013	.73		
Q14. Provide day to day care for the dying person	0.889 (0.852, 0.917)	.006	.79		
Q15. Access equipment required for care	0.897 (0.862, 0.929)	.006	.81		
Q16. Access culturally appropriate support	0.853 (0.816, 0.891)	.009	.73		
Q17. Access emotional support for myself	0.751 (0.670, 0.804)	.021	.56		
Factual knowledge	0.809 (0.721, 0.872)	.004	.65	.924/.925	3.05 (2.60)
Q18. I know the law regarding dying at home	0.711 (0.641, 0.783)	.005	.51		
Q19. I feel confident in knowing what documents you need to complete in planning for death	0.835 (0.789, 0.873)	.012	.70		
Q20. I know how to navigate the health care system to support a dying person to receive care	0.907 (0.870, 0.935)	.010	.82		
Q21. I know how to navigate funeral services and options	0.741 (0.671, 0.791)	.013	.55		
Q22. I know how to access palliative care in my area	0.872 (0.838, 0.897)	.011	.76		
Q23. I have sufficient understanding of illness trajectories to make informed decisions around medical treatments available and how that will shape quality of end of life	0.786 (0.740, 0.831)	.003	..62		
Q24. I know about the contribution the funeral home staff can make at end of life	0.707 (0.650, 0.771)	.008	.50		
Experiential Knowledge	0.623 (0.467, 0.743)	.014	.39	.868/.871	6.26 (2.12)
Q25. Increased my emotional strength to help others with death and dying processes	0.710 (0.634, 0.780)	.008	.50		
Q26. Led me to re-evaluate what is important and not important in life	0.676 (0.575, 0.746)	.006	.46		
Q27. Developed my wisdom and understanding	0.843 (0.776, 0.887)	.013	.71		
Q28. Made me more compassionate toward myself	0.731 (0.654, 0.785)	.008	.53		
Q29. Provided me with skills and strategies when facing similar challenges in the future	0.829 (0.769, 0.872)	.011	.69		

[1] Range is from 0–10, *β* standardised regression coefficient. r^2 squared regression coefficient. *CI* bootstrapped confidence interval. *A* Cronbach's alpha

Ω Coefficient omega

demonstrating little variability in DLI to be explained by demographics. The following demographic variables were not significantly associated with the DLI at the 0.05 significance level; gender, highest level of education, employment status, annual household income, relationship status, caring for dependent adults, having a chronic mental illness, and belief in an afterlife. Due to small subgroup size, associations could not be explored for individuals with terminal illness.

The eta-square statistic for age reports a moderate effect size. Post hoc analysis using the Games-Howell criterion for significance indicated a positive relationship with age, with the DLI mean score higher for > 58 year olds (M = 3.11, SD = 0.77) than in 38–47 year olds

Table 3 Convergent validity and discriminant validity of the Death Literacy Index (r)

Subscales	Objective knowledge of death system	Coping with Death Scale	Actions relating to discussing death and dying – community	Actions relating to discussing death and dying-family	UCLA Loneliness Scale
Practical Knowledge	.197**	.631**	.342**	.417**	-.104*
Doing hands on care	.134**	.403**	.242**	.257**	-.038
Talking support	.195**	.657**	.331**	.445**	-.141**
Community Knowledge	.209**	.538**	.348**	.302**	-.165**
Support groups	.167**	.416**	.292**	.237**	-.166**
Accessing help	.199**	.525**	.321**	.292**	-.128**
Factual knowledge	.234**	.630**	.247**	.305**	-.122**
Experiential Knowledge	.132**	.520**	.302**	.401**	-.050
DLI Total	.251**	.746**	.394**	.451**	-.144**

Correlation is significant at the 0.05 level (1-tailed).*, Correlation is significant at the 0.01 level (1-tailed).**

(M = 2.76, SD = 0.69) or 28–37 year olds (M = 2.61, SD = 0.52), and the DLI mean score higher in 48–57 year olds than 28–37 year olds. The relationship with age was however not linear, with 28–37 year olds reporting a lower DLI mean score than 18–27 year olds (M = 2.90, SD = 0.61).

Discussion

This is the first study to validate the Death Literacy Index (DLI; [13]) in the UK, with evidence suggesting that the DLI is a reliable and valid measure of death literacy in this population. In addition to providing the psychometric evaluation needed for this measure to be used in the UK, this study is one of the first to validate the DLI in an international context. This suggests that the measure performs well outside of Australia where it was originally developed [13]. The authors are aware of ongoing efforts to validate the DLI in Sweden, Belgium and the Netherlands.

The original higher-order factor structure was a good fit for the UK data. Model fit was improved with the addition of a substituted item for the UK context on the contribution of 'funeral home staff' (replacing 'cemetery staff') which loaded more strongly on to the 'factual knowledge' subscale. The authors would therefore recommend use of this substituted item when administering the DLI in the UK. All other items loaded well on to their respective subscales. The lowest loading items referred to administering injections, lifting a person or assisting to transfer them, and talking to a child about bereavement. The item relating to administering injections would not be applicable across all EoLC situations and so may be expected to not explain a high degree of variance. The other two items not loading as strongly is more unexpected and may reflect a lack of direct involvement in EoLC within the sample. This is worthy of further investigation, and a cognitive interviewing study is being undertaken by the lead author to assess the content validity of the DLI in the UK.

The DLI subscales possess good reliability (i.e., internal consistency), with the original DLI authors suggesting that individual subscales could be used alone if reliable [13]. Interpretability is also good, however floor effects were observed on the 'factual knowledge' subscale. Indeed, this was the subscale with the lowest scaled mean score for the UK sample. However, as the floor effects only just meet the threshold, this is unlikely to be a major cause for concern, with the DLI capable of measuring high and low death literacy. The DLI is also valid having demonstrated the expected positive and negative associations with related constructs, evidencing convergent and discriminant validity. Reassuringly, the DLI was moderately associated with the Coping with Death Scale [14], demonstrating that death literacy and death competency are related but distinct constructs. Effect sizes for the correlations with objective knowledge of the death system and actions regarding death and dying were smaller than expected and may reflect measurement error as validated measures were not used in order to restrict survey length. Although it does not measure understanding of the death system as a whole, future validation studies may consider using the Palliative Care Knowledge Scale (PaCKS; [41]) to assess objective knowledge. Effect sizes for the negative correlations between the DLI and loneliness were also smaller than expected. A consideration is that a construct such as perceived functional social support may be expected to be more highly correlated with death literacy than loneliness and could be explored in future research.

Known groups validity was demonstrated with individuals with professional or lived experience of EoLC reporting higher levels of death literacy as expected.

Table 4 Known-groups validity of the death literacy index

Subscales	I work or have worked with people at end of life, including volunteering ($n=41$)			I work or have worked in a job where I support/ed people through grief and loss, including volunteering ($n=27$)			I have attended training on helping people with dying, grief or bereavement ($n=29$)			I am carer/family member/partner/spouse/friend of someone who is thought to be in the last few years of their life ($n=37$)			I am a bereaved carer/family member/partner/spouse/friend of someone who has died in the last 2 years ($n=67$)		
	Mean[1] (SD)	Welch's F statistic and sig level	Eta sq	Mean (SD)	Welch's F statistic and sig level	Eta sq	Mean (SD)	Welch's F statistic and sig level	Eta sq	Mean (SD)	Welch's F statistic and sig level	Eta sq	Mean (SD)	Welch's F statistic and sig level	Eta sq
Practical Knowledge	6.94 (1.67)	48.73***	0.130	6.55 (1.59)	24.27***	0.066	6.45 (1.78)	18.64***	0.061	5.88 (1.71)	9.45**	0.030	5.80 (1.86)	11.31**	0.036
Doing hands on care	6.59 (2.47)	29.78***	0.106	6.02 (2.45)	11.71**	0.046	5.71 (2.81)	6.49*	0.032	5.00 (2.25)	2.82	0.010	5.13 (2.39)	5.99*	0.020
Talking support	7.30 (1.67)	35.18***	0.080	7.08 (1.88)	15.82***	0.045	7.20 (1.64)	24.32***	0.055	6.76 (1.89)	12.71**	0.036	6.47 (2.18)	9.55**	0.030
Community Knowledge	6.45 (2.34)	40.91***	0.147	5.93 (2.33)	17.58***	0.073	6.55 (2.52)	28.18***	0.124	4.68 (2.37)	3.01	0.013	5.54 (2.29)	25.87***	0.086
Support groups	6.55 (2.64)	17.21***	0.070	6.69 (4.49)	15.19***	0.061	6.77 (2.81)	14.00**	0.068	5.05 (2.55)	0.49	0.002	5.74 (2.46)	8.92**	0.031
Accessing help	6.35 (2.64)	51.14***	0.164	5.17 (2.77)	12.62**	0.053	6.33 (2.86)	31.89***	0.128	4.31 (2.80)	5.28*	0.022	5.34 (2.76)	33.21***	0.108
Factual Knowledge	4.92 (3.15)	24.40***	0.128	4.13 (3.10)	8.01**	0.050	5.17 (2.91)	24.82***	0.127	3.64 (2.96)	6.04*	0.033	4.57 (2.93)	31.94***	0.127
Experiential Knowledge	7.43 (1.97)	28.97***	0.086	7.33 (1.92)	19.01***	0.058	7.62 (1.73)	32.94***	0.083	6.76 (1.77)	12.49**	0.034	7.19 (1.91)	33.74***	0.090
DLI Total	6.44 (1.83)	53.83***	0.203	5.98 (1.90)	21.52***	0.106	6.45 (1.88)	37.74***	0.167	5.24 (1.70)	11.69**	0.049	5.77 (1.81)	41.02***	0.143

[1] Range is from 0–10 * Significant at the $p<0.05$ level, ** Significant at the $p<0.01$ level, ***Significant at the $p<0.001$ level. Eta Sq. interpreted as .01 "small"; .06 "medium"; .14 "large" (Cohen, 1988)

Table 5 Median, range, interquartile range and floor and ceiling effects of the Death Literacy Index

Subscales	*Mdn*	Range	IQR	Floor & Ceiling effects
Practical Knowledge	25.0	8–40 (possible range is 8–40)	8.0	3 participants (0.3%) had the lowest possible total score, and 2 participants (0.5%) had the highest possible total score
Doing hands on care	12.0	4–20 (possible range is 4–20)	5.0	12 participants (3.0%) had the lowest possible total score, and 9 participants (2.3%) had the highest possible total score
Talking support	14.0	4–20 (possible range is 4–20)	4.0	5 participants (1.3%) had the lowest possible total score, and 16 participants (4.1%) had the highest possible total score
Community Knowledge	25.0	9–45 (possible range is 9–45)	13.0	13 participants (3.3%) had the lowest possible total score, and 5 participants (1.3%) had the highest possible score
Support groups	12.0	4–20 (possible range is 4–20)	6.0	19 participants (4.8%) had the lowest possible total score, and 17 participants (4.3%) had the highest possible total score
Accessing help	12.0	5–25 (possible range is 5–25)	9.0	57 participants (14.5%) had the lowest possible total score, and 8 participants (2%) had the highest possible total score
Factual Knowledge	14.0	7–35 (possible range is 7–35)	11.0	61 participants (15.5%) had the lowest possible total score, and 4 participants (1%) had the highest possible score
Experiential Knowledge	18.0	5–25 (possible range is 5–25)	5.0	5 participants (1.3%) had the lowest possible total score, and 17 participants (4.3%) had the highest possible total score
DLI Total	84.0	40–143 (possible range is 29–145)	29.0	No participants had the lowest or highest possible total score

Table 6 Scaled mean scores for the UK on DLI and its subscales

Subscales	UK Population ($n = 394$)Scaled Mean
Practical Knowing (TOTAL 8 items)	5.35 (1.91)
Hands on support (4 items)	4.73 (2.43)
Talking support (4 items)	5.96 (2.16)
Community Knowledege (TOTAL 9 items)	4.48 (2.29)
Community support groups (4 items)	5.06 (2.43)
Accessing help (5 items)	3.91 (2.77)
Factual Knowledge (7 items)	3.05 (2.60)
Experiential Knowledge (5 items)	6.16 (2.12)
DLI TOTAL	4.76 (1.73)

[1] Range is from 0–10

However, for the subgroup identifying as a 'carer/family member/partner/spouse/friend of someone who is thought to be in the last few years of their life' scores were not higher on all of the DLI subscales. This may be due to how this group were defined, introducing significant heterogeneity. For example, the group may reflect individuals who are not directly involved in providing support for an individual at end-of-life. The group may also reflect individuals who are at the start of their caring journey, which raises an important question around when death literacy is developed along the caregiving trajectory. Using the DLI in research with carers could help inform our theoretical understanding of how and when death literacy develops, and the subsequent impact. There is increasing interest in the risk and protective factors for complicated grief [42], with greater preparedness for death, for example, shown to be a protective factor [43, 44]. With the DLI shown to be a valid and reliable measure of death literacy within the UK, there is an opportunity to develop robust evidence on how components of death literacy may improve end-of-life experiences both for individuals with life-limiting diagnoses and their close persons.

The current study provides, for the first time, UK population level benchmarks for the DLI total score and the various subscales. These benchmarks can be used to inform which components of death literacy may be most

Table 7 Summary of significant relationships between demographic variables and the death literacy index

	Direction of relationship	Welch F statistic and significance level	Eta Sqr
Age	Positive	8.39***	0.071
Rural location	Positive	3.41*	0.017
Having children	Positive	13.14***	0.032
Chronic physical health condition	Positive	4.15*	0.012
Religious background	Positive	8.16**	0.022

* Significant at the $p < 0.05$ level, ** Significant at the $p < 0.01$ level, ***Significant at the $p < 0.001$ level. Eta Sq. interpreted as .01 "small"; .06 "medium"; .14 "large" (Cohen, 1988)

valuable to target at a population level through public health interventions and will be useful for researchers and practitioners to use as population baselines to compare scores within their own communities. Individuals from the UK appear to have, relative to other subscales, high levels of experiential knowledge and the ability to talk about death and dying. It must however be recognised that all population level benchmarks are near the mid-point of each subscale, and there is considerable opportunity to strengthen capacity in all areas of death literacy. For example, a recent survey in Northern Ireland [45] reported significant barriers to individuals talking about death and dying, such as fear of upsetting self or others and apprehension at navigating sensitive conversations. Key areas to strengthen capacity at a population level are around factual knowledge and accessing help. This is supported by recent UK research reporting a lack of familiarity with EoLC terminology and processes, and a lack of awareness on how to access support [46]. There is a lack of formally evaluated community-based EoLC interventions [12]. In addition to informing best value targets for novel interventions, the validation of the DLI in a UK context also provides a useful measure to evaluate the impact of such initiatives.

The population level benchmarks established in the current UK study are similar to the levels of death literacy reported in the Australian population [13]. However, the timing of both studies is a key contextual difference with the Australian data collected pre-pandemic, and the UK data mid-pandemic. Within the context of a mass-bereavement event, it is reasonable to assume that there would be greater opportunity for experiential learning, with the experiential knowledge subscale reporting the highest scaled mean score for the UK sample. This underscores the value of using the DLI to measure population trends in death literacy over time, with measurement of death literacy a key recommendation in a recent policy report [47]. It is an open-question as to whether the COVID-19 pandemic has contributed positively to communities' capacity to provide EoLC, and indeed the extent to which death literacy can be sustained over time within communities. There is a desire from the general public to learn from those with professional and lived experience of EoLC [45], with the challenge being how to translate this into community-based interventions without increasing the recognised burden on informal carers.

As with the validation of the DLI in the original Australian sample [13], there was little socio-demographic variability in the current study implying the measure is applicable across social contexts. Although having a religious background and a chronic physical health condition report a significant relationship with higher levels of death literacy, the effect size is small. This is perhaps surprising given the opportunity to support individuals to develop death literacy in faith communities and health and social care settings. Only age reported a moderate effect size which may be expected, given that death literacy is suggested to develop from personal experience [10], with exposure to death, dying and loss accumulating over time. However, young adults have previously described experiencing exclusion from conversations relating to care decisions, serious illness and death, leading to a feeling of being ill-prepared [48]. This emphasises the importance of a life-course approach to death literacy, with respondents in our previous research suggesting that death literacy should be provided equal status to sexual health education in school settings [45]. The relationship between age and death literacy is not strictly linear in the current study, 28–37 year olds reporting a lower DLI mean score than 18–27 year olds, and there is a significant relationship between having children and higher levels of death literacy. Optimistically, this may reflect public health approaches to EoLC becoming more embedded for younger generations. The majority of research on public health approaches to EoLC has however focused on older adults [12] or solely on understanding of palliative and end of life care [48]. A more in-depth understanding of death literacy across the life-course would be a valuable focus for future research.

The current study has a number of strengths. The use of a population sample representative of age, gender and ethnicity provides confidence in the benchmarks, and addresses a limitation with the previous validation study [13], and the validation of death and dying measures more broadly [49]. The study followed best practice COSMIN guidelines [15] for assessment of structural, construct validity, internal consistency, and interpretability. However, the sample size in two subgroups for assessment of known groups validity was inadequate according to COSMIN recommendations. We also were not able to assess cross-cultural validity as planned in our pre-registered protocol, due to sample size within subgroups. Future research should focus on ascertaining the performance of the measure across different populations, in different age groups for example. The content validity of the measure was not assessed prior to the current study (the replacement item was developed by the research team), and ongoing research will address this important gap. The method of recruitment (via a panel) must also be considered, where self-selection of interested individuals may have led to an over-estimation of the levels of death literacy. The responsiveness of the DLI is still uncertain and given the potential use of the measure in evaluating public health interventions, this will be a priority to ascertain going forward. Future research with informal carers in particular is recommended, to ensure the

measure performs well in this important context. Lastly, it must be recognised that the aim of this study was to establish the psychometric properties of the DLI at a population-level.

Conclusion

The DLI is a valid and reliable measure of death literacy for use by researchers and practitioners in a UK context. Developing public health approaches to palliative care is a priority for the majority of palliative care service providers in the UK [50], yet the evidence base for public health approaches to palliative care is lacking with few formal evaluations [12]. The current study makes a novel contribution to these efforts by providing population-level benchmarks for the UK of the various components of death literacy to guide intervention development, and by evidencing the validity and reliability of the DLI as a measure of death literacy to be used to evaluate public health initiatives.

Abbreviations

DLI: Death literacy index; EoLC: End of life care.

Acknowledgements

We would like to thank Prof Debbie Horsfall for her early contribution to the design of the study.

Authors' contributions

All authors contributed to the conception and design of the work, LG-W, JG & PT the data collection and analysis, LG-W drafted the work, and all authors approved the submitted version and agree to be personally accountable for the author's own contributions and to ensure questions related to accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature. All authors read and approved the final manuscript.

Funding

This research was supported by the Covid-19 Online Research Support Fund from the School of Psychology, Queen's University Belfast.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request. For a copy of the full Death Literacy Index measure, please contact Prof Rosemary Leonard (r.leonard@westernsydney.edu.au).

Declarations

Ethics approval and consent to participate

Research ethics approval was provided by the Queen's University Belfast Engineering and Physical Sciences Faculty Research Ethics Committee (Reference; EPS 20_218) on 11th September 2020. The study was conducted in accordance with the Declaration of Helsinki and participants completed an informed consent statement prior to completion of the survey.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Author details

[1]Centre for Improving Health-Related Quality of Life, School of Psychology, Queen's University Belfast, Belfast BT7 1NN, UK. [2]School of Social Sciences and Psychology, Penrith Kingswood Campus, Western Sydney University Locked Bag 1797, Penrith, NSW 2751, Australia. [3]School of Psychology, National University of Ireland Galway, University Road, Galway, Ireland.

Received: 12 May 2022 Accepted: 2 August 2022
Published online: 13 August 2022

References

1. Sleeman KE, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. Lancet Glob Health. 2019;7(7):e883–92.
2. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med. 2017;15(1):102.
3. Kellehear A. The end of death in late modernity: An emerging public health challenge. Crit Public Health. 2007;17(1):71–9.
4. Kellehear A. Health-promoting palliative care: Developing a social model for practice. Mortality. 1999;4(1):75–82.
5. Earle S, Bartholomew C, Komaromy C, editors. Making sense of death, dying and bereavement: An anthology. UK: Sage; 2009. p. 224. [cited 2022 Feb 28]. Available from: http://www.sagepub.com/booksProdDesc.nav?level1=M00&currTree=Subjects&prodId=Book233015.
6. Rosenberg J, Yates P. Transition from conventional to health-promoting palliative care: an Australian case study. In: Conway S, editor. Governing Death and Loss: Empowerment, Involvement, and Participation [Internet]. United Kingdom: Oxford University Press; 2011. p. 99–107. [cited 2022 Feb 28]. Available from: http://www.oup.com.au/titles/academic/medicine/9780199586172.
7. Horsfall D, Noonan K, Leonard R. Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities. Health Sociol Rev. 2012;21(4):373–82.
8. Horsfall D. Developing compassionate communities in Australia through collective caregiving: A qualitative study exploring network-centred care and the role of the end of life sector. Ann Palliat Med. 2018;1(7):S42-51.
9. Leonard R, Horsfall D, Rosenberg J, Noonan K. Carer experience of end-of-life service provision: a social network analysis. BMJ Support Palliat Care. 2020;10(2):e20–e20.
10. Leonard R, Noonan K, Horsfall D, Psychogios H, Kelly M, Rosenberg JP, et al. Death Literacy Index: A Report on its Development and Implementation [Internet]. 2020 [cited 2022 Feb 28]. Available from: https://researchdirect.westernsydney.edu.au/islandora/object/uws%3A56211/
11. Noonan K, Horsfall D, Leonard R, Rosenberg J. Developing death literacy. Prog Palliat Care. 2016;24(1):31–5.
12. Sallnow L, Richardson H, Murray SA, Kellehear A. The impact of a new public health approach to end-of-life care: A systematic review. Palliat Med. 2016;30(3):200–11.
13. Leonard R, Noonan K, Horsfall D, Kelly M, Rosenberg JP, Grindrod A, et al. Developing a death literacy index. Death Stud. 2021;0(0):1–13.
14. Robbins RA. Bugen's Coping with Death Scale: Reliability and Further Validation. OMEGA - J Death Dying. 1991;22(4):287–99.
15. Mokkink LB, Prinsen CA, Patrick DL, Alonso J, Bouter LM, de Vet HC, et al. COSMIN Study Design checklist for Patient-reported outcome measurement instruments. Amsterdam: 2019.
16. 2011 Census data - Office for National Statistics [Internet]. [cited 2022 Feb 28]. 2011 Census data - Office for National Statistics [Internet]. [cited 2022 Feb 28]. Available from: https://www.ons.gov.uk/census/2011census/2011censusdata.
17. Qualtrics XM // The Leading Experience Management Software [Internet]. Qualtrics. [cited 2022 Feb 28]. Available from: https://www.qualtrics.com/uk/.
18. Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A Short Scale for Measuring Loneliness in Large Surveys: Results From Two Population-Based Studies. Res Aging. 2004;26(6):655–72.

19. Neimeyer RA, Moser RP, Wittkowski J. Assessing Attitudes Toward Dying and Death: Psychometric Considerations. OMEGA - J Death Dying. 2003;47(1):45–76.
20. Russell D, Peplau LA, Cutrona CE. The revised UCLA Loneliness Scale: concurrent and discriminant validity evidence. J Pers Soc Psychol. 1980;39(3):472.
21. de Winter JCF, Dodou D, Wieringa PA. Exploratory Factor Analysis With Small Sample Sizes. Multivar Behav Res. 2009;44(2):147–81.
22. Nunnally JC, Nunnaly JC. Psychometric Theory. McGraw-Hill; 1978. p. 826.
23. Worthington RL, Whittaker TA. Scale Development Research: A Content Analysis and Recommendations for Best Practices. Couns Psychol. 2006;34(6):806–38.
24. Gorsuch RL. Factor Analysis: Classic Edition. 2nd ed. New York: Routledge; 2014. p. 464.
25. Velicer W, Fava J. An Evaluation of the Effects of Variable Sampling On Component, Image, and Factor Analysis. Multivar Behav Res - Multivar BEHAV RES. 1987;22:193–209.
26. World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. Jama. 2013;310(20):2191–4.
27. Terwee CB, Bot SDM, de Boer MR, van der Windt DAWM, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol. 2007;60(1):34–42.
28. Byrne BM. Structural Equation Modeling With AMOS: Basic Concepts, Applications, and Programming, Third Edition. 3rd ed. New York: Routledge; 2016. p. 460.
29. Curran PJ, West SG, Finch JF. The robustness of test statistics to nonnormality and specification error in confirmatory factor analysis. Psychol Methods. 1996;1(1):16–29.
30. Bentler PM. EQS structural equations program manual. Encino, CA: Multivariate software; 1995.
31. Kline RB. Principles and Practice of Structural Equation Modeling, Fourth Edition. Guilford Publications; 2015.
32. Tabachnick BG, Fidell LS, Ullman JB. Using multivariate statistics. Seventh edition. NY, NY: Pearson; 2019.
33. Schumacker RE, Lomax RG. A Beginner's Guide to Structural Equation Modeling. Psychology Press; 2004.
34. Kenny DA, McCoach DB. Effect of the Number of Variables on Measures of Fit in Structural Equation Modeling. Struct Equ Model Multidiscip J. 2003;10(3):333–51.
35. Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. Struct Equ Model Multidiscip J. 1999;6(1):1–55.
36. Field A. Discovering Statistics Using SPSS. 3rd ed. Los Angeles: SAGE Publications; 2009. p. 856.
37. Nunnally JC. Psychometric theory. New York: McGraw-Hill; 1978.
38. Cohen J. Statistical power analysis for the behavioral sciences. 2nd ed. Hillsdale: L. Erlbaum Associates; 1988.
39. Bollen KA, Stine RA. Bootstrapping goodness-of-fit measures in structural equation models. Sociological Methods & Research. 1992;21(2):205–29.
40. Nevitt J, Hancock G. Performance of Bootstrapping Approaches to Model Test Statistics and Parameter Standard Error Estimation in Structural Equation Modeling. Struct Equ Model Multidiscip J. 2001;8(3):353–77.
41. Kozlov E, Carpenter BD, Rodebaugh TL. Development and validation of the Palliative Care Knowledge Scale (PaCKS). Palliat Support Care. 2017;15(5):524–34.
42. Mason TM, Tofthagen CS, Buck HG. Complicated Grief: Risk Factors, Protective Factors, and Interventions. J Soc Work End-Life Palliat Care. 2020;16(2):151–74.
43. Kim Y, Carver CS, Spiegel D, Mitchell HR, Cannady RS. Role of family caregivers' self-perceived preparedness for the death of the cancer patient in long-term adjustment to bereavement. Psycho-oncology. 2017;26(4):484–92.
44. Vanderwerker LC, Prigerson HG. Social support and technological connectedness as protective factors in bereavement. J Loss Trauma. 2004;9(1):45–57.
45. Graham-Wisener L, Nelson A, Byrne A, Islam I, Harrison C, Geddis J, et al. Understanding public attitudes to death talk and advance care planning in Northern Ireland using health behaviour change theory: a qualitative study. BMC Public Health. 2022;22(1):906.
46. Marie Curie. Public attitudes to death and dying [Internet]. 2021. Available from: https://www.mariecurie.org.uk/globalassets/media/documents/policy/public-attitudes-to-death-and-dying-report-final.pdf
47. Marie Curie. Creating a Death Literate Society [Internet]. 2022. Available from: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/creating-a-death-literate-society.pdf.
48. Mallon A, Hasson F, Casson K, Slater P, McIlfatrick S. Young adults understanding and readiness to engage with palliative care: extending the reach of palliative care through a public health approach: a qualitative study. BMC Palliat Care. 2021;20(1):1–3.
49. Groebe B, Strupp J, Eisenmann Y, Schmidt H, Schlomann A, Rietz C, et al. Measuring attitudes towards the dying process: A systematic review of tools. Palliat Med. 2018;32(4):815–37.
50. Paul S, Sallnow L. Public health approaches to end-of-life care in the UK: an online survey of palliative care services. BMJ Support Palliat Care. 2013;3(2):196–9.

Publisher's Note

BMC Public Health

RESEARCH

Open Access

Understanding public attitudes to death talk and advance care planning in Northern Ireland using health behaviour change theory: a qualitative study

L. Graham-Wisener[1*], A. Nelson[2], A. Byrne[2], I. Islam[2], C. Harrison[3], J. Geddis[1] and E. Berry[1]

Abstract

Objectives: Advance care planning is a key preparatory step in ensuring high-quality palliative and end of life care, and should be considered as a process, beginning with community-level conversations among lay persons. There is, however, indication that death talk among community-dwelling adults is not occurring, and there is a dearth of research examining why this is the case. This study aims to provide the first examination of barriers and facilitators to talking about death and dying among the general population in a UK region (Northern Ireland), and to provide a novel application of health behaviour change theory towards developing a theoretical understanding of the sources of this behaviour.

Methods: The study involved qualitative analysis of responses ($n = 381$ participants) to two open-ended questions within a cross-sectional online survey, with recruitment via social media of adults currently living in Northern Ireland. Reflexive thematic analysis was conducted on open text responses per question, with the barriers and facilitators mapped on to health behaviour change models (the Behaviour Change Wheel COM-B and the Theoretical Domains Framework).

Results: The findings evidence a myriad of barriers and facilitators to engaging in death talk, with themes aligning to areas such as lack of acceptance of death in social contexts and fear of upsetting self or others, and a need to improve interpersonal communication skills for facilitating conversations and improve knowledge of the existing services around death and dying. A theoretical understanding of the drivers of death talk is presented with findings mapped across most components of the COM-B Behaviour Change Model and the Theoretical Domains Framework.

Conclusions: This study contributes to a small but emergent research area examining barriers and facilitators to talking about death and dying. Findings from this study can be used to inform new public health programmes towards empowering adults to have these conversations with others in their community towards upstreaming advance care planning.

Keywords: Palliative care, Public health, Death and dying, Behaviour change, Advance care planning, ACP

Background

In the UK, death rate and complexity of need for palliative and end-of-life care (PEOLC) patients are projected to increase substantially over the next two decades alongside the demand for PEOLC provision [1, 2]. This

*Correspondence: l.graham-wisener@qub.ac.uk

[1] Centre for Improving Health-Related Quality of Life, School of Psychology, Queen's University Belfast, Belfast, UK
Full list of author information is available at the end of the article

is reflective of international trends [3] representing increased provision of PEOLC as a global public health need. A key preparatory step in delivering high-quality PEOLC is advance care planning (ACP), cited across UK strategy documents and within quality indicators for good quality PEOLC [4–7]. ACP is an ongoing process that supports adults of any age in sharing their values, goals and preferences regarding future medical care during serious and chronic illness [8], and is evidenced to positively impact the quality of PEOLC [9]. There are however reports that indicate only a minority of adults in the UK have engaged in an ACP conversation [10, 11]. In acknowledging ACP as a continuous process across the life course [8] where an individual's readiness for engagement may vary [12], there is value in considering how to "upstream" and "normalize" community-led conversations around death and dying more broadly [13].

The shift towards considering discussion of death and dying in the community aligns to the 'new public health approach' within palliative care [14]. The Health Promoting Palliative Care model (HPPC; [15]) advocates for movement towards a sustainable social model of end-of-life care, where death and dying are considered within the community context of everyday life and where each social actor is empowered to contribute. Advocates of HPPC recommend that at present building community capacity should be prioritized over further mainstream palliative care provision [16, 17]. A key principle of building community capacity includes normalizing death and preparing communities for end of life [17]. The mechanism for achieving this is through developing death literacy, defined as a set of knowledge and skills that make it possible to gain access to, understand and act upon end-of-life and death care options [18]. This includes the ability of individuals to provide talking support to a close friend, or child about death and dying [19], increasing readiness and providing a supportive context for community-based ACP conversations.

A significant proportion of UK adults report not being comfortable discussing death and dying with family and friends [20]. Most of the existing research on barriers to talking about death and dying has been conducted within the context of ACP with healthcare professionals (e.g. [21–23]), clinical populations of adults with a life-threatening illness (e.g. [24–26]), or with older adults (e.g. [27–29]). A recent call for future HPPC research resonates with the need to focus more "upstream", stating the importance of approaching issues with the full population of interest, including 'hidden publics' and younger adults [14]. The authors recommend the use of surveys to evaluate the perceptions and experiences of the wider community, rather than only those defined as terminally ill [14]. Although there is an emergent evidence-base for the impact of new public health approaches to end-of-life care [14], a lack of observational research hampers capacity to address the dearth of high-quality interventions seeking early engagement with the general population.

In developing the evidence-base on which to inform interventions to increase talking about death and dying at a population level, it is important to develop a theoretically informed understanding of the target behaviour and associated change processes [30]. Authors have previously acknowledged the dearth of theoretically-informed interventions in PEOLC [31, 32]. Prominent within public health, health behaviour change theory including the Behaviour Change Wheel (BCW, [33]) and Theoretical Domains Framework (TDF, [34]) provide a systematic and theoretical basis for understanding and changing behaviour. In comparison to individual theoretical models, they enable a more comprehensive examination of a range of modifiable constructs, including internal factors and those pertaining to the external physical and social environment. The TDF and the inner part of the BCW, the Capability Opportunity Motivation-Behaviour model (COM-B), can be used to understand the Capability, Opportunity, and Motivational sources of any behaviour which can then inform the development of evidence and theory-based interventions. Behaviour change theory is increasing in use within PEOLC research (e.g. [35, 32, 36]) including application within a systematic review on implementation of ACP [37].

The question of how best to support listening to and incorporating individuals' preferences around end-of-life aligns to unanswered research questions prioritised by people likely to be within the last few years of life, current and bereaved carers and healthcare professionals [38, 39]. With exception (e.g., [40]), there is limited research examining barriers and facilitators to talking about death and dying in general population samples in the UK. There is however recognition of the importance of building community capacity in providing PEOLC, including from the perspective of specialist palliative care providers [41] and general practitioners [42]. This study aims to provide the first exanimation of barriers and facilitators to talking about death and dying in a UK region (Northern Ireland). Secondly, the study aims to provide a novel application of health behaviour change theory towards informing future evidence-based interventions to increase discussion of this important topic in the general population.

Methods

Design and setting

The study involved qualitative analysis of responses ($n = 381$ participants) to two open-ended questions within a cross-sectional mixed-methods online survey. Although underutilized, mixed-methods/qualitative

surveys have been recommended as a 'best fit' when seeking multiple perspectives from large populations, when the topic suits a 'wide angle lens', and when wishing to encourage disclosure and participation in regards to a sensitive topic [43]. Reporting of findings is informed by CHERRIES guidance for reporting Internet surveys [44] and COREQ guidance for reporting qualitative research [45].

The setting for the study is a region of the United Kingdom, Northern Ireland (population circa 1.9 million). In Northern Ireland, the local death rate is projected to increase by 31 per cent by 2031 [1], as calculated pre-pandemic, the highest proportional increase across the UK nation states. A recent survey conducted in 2019 indicates only a minority of the population (7%) have previously engaged in an ACP conversation [11].

Sampling and recruitment

The sampling frame for this study defined community as a member of the public currently living in Northern Ireland. Eligibility criteria included adults (≥ 18 years of age) who have the capacity to express their opinion.

Convenience sampling was used with an open-survey link shared via social media (Twitter & Facebook) by the research team using a dedicated handle (@PADDNI_Research). Several organisations (e.g., charities, public-facing bodies, private businesses) were invited to share the survey link and were provided with posters to display on their premises. Participants were provided with a participant information sheet informing them of the purpose of the study, approximate survey completion time, which data are stored, where, and for how long, and details of the research team. Participants completed an informed consent statement prior to completion of the survey and provided informed consent for use of their data again at survey completion [46]. Participants were not contacted individually. No personal data were collected. Furthermore, participants had no prior relationship with the researchers. This study was approved by the QUB EPS Faculty Research Ethics Committee.

Survey Design and Implementation

The survey was originally developed by the co-authors at Cardiff University [47] in collaboration with the One Wales Palliative Care Program of the National End of Life Care Board, informed by findings from the James Lind Alliance Palliative and End of Life Care Priority Setting Partnership [38, 39]. The aim of the survey was to understand attitudes towards death and dying, with included domains on fears about death and dying, preferences and priorities around EoLC, knowledge around terminologies commonly used in EoLC and understanding about ACP, EoLC plans and communication around death and dying. An extensive literature review informed the domains of interest and the survey questions were refined by a group of experts in this field, including volunteer research partners. Minor modifications were made by the research team to the original survey for the Northern Ireland context, with input of clinician and policy colleagues at Marie Curie Northern Ireland.

The 41-item online survey was hosted on Qualtrics [Qualtrics, Provo, UT], with items presented to participants across 7 pages (range 1–17 items per page) and in a standardized order. Respondents were able to review and change their answers, and in line with guidelines [46] a withdraw button was included on each page. There were no forced responses to items. No incentives were offered to participants. Prior to data collection, the survey was piloted with 12 participants with no amendments made. Data was collected between 20th January and 18th April 2019, and the median time of survey completion was 14.2 min.

Towards understanding communication around death and dying, this study is a focused qualitative analysis of two open-ended survey items from the larger survey-

i) *"As a society, how much do we talk about death and dying in Northern Ireland? If not enough, how do you think this can be increased*?" (Question 5)
ii) *"Is there anything that prevents you from talking about death and dying? If yes, please state"* (Question 14)

Analysis

Data were exported from Qualtrics [Qualtrics, Provo, UT] to a Microsoft Word Document. In total, 924 respondents consented to participate in the survey, after 2 respondents were removed as providing multiple responses (identified by Qualtrics as multiple identical responses from same IP address < 12 h). Data were scrutinized for i) duplicate responses by examining sociodemographic variables (age, gender, education) alongside responses, and ii) responses completed in < 5 min with participants withdrawing at first opportunity, with 2 responses removed. In total, 61% of responses ($n = 562$) completed the survey by providing informed consent for their data to be used at the end of the survey. A total of 381 participants provided responses to the two open-ended questions analysed in this study: with 179 responses to the barriers question and 326 responses to the facilitators question.

This study adopts a subtle realist epistemological stance within an interpretative paradigm, which recognises the subjectivity of human experience but is concerned with identifying common patterns across subjective narratives which denote collective experience. Reflexive thematic

analysis was conducted on open text responses for each question separately using Microsoft Word and Microsoft Excel to track codes and notes [48]. This method of analysis fitted the subtle realist stance and provided sufficient flexibility to explore the range of perspectives and experiences conveyed by a large cohort of participants to address the broad research aim [43]. This followed a six-stage process which includes familiarisation with the data; inductive coding; exploring potential themes; reviewing and confirming themes; labelling and defining themes; and reporting and interpretation of themes [48]. Codes were identified by a lead analyst (JG, BSc) and were iteratively reviewed to ensure that these accurately captured relevant units of data [49]. A coding tree was developed from confirmed codes in table format on MS Word, which guided the identification of subthemes and overarching themes. Themes/subthemes were iteratively constructed and discussed with the wider analysis team (LGW, PhD & EB, PhD) and were cross-checked with codes and quotes to ensure that these remained closely bound to the data. Final themes/subthemes were established following rigorous discussion. In line with recent recommendations, the reflexive thematic analysis was conducted inductively, with no theoretical constraints on the identification of themes from the COM-B and TDF [50]. Team meetings were held frequently throughout the analysis to reflect on progressive interpretation of the data and reflexive notes. This ensured that reflexive practice was maintained, supporting a transparent and credible analytic process [49]. Barriers and facilitators were then mapped onto the COM-B [33] and the TDF, where they were deemed to conceptually fit [43]. This mapping process involved developing descriptions derived from themes/subthemes, which are aligned with the corresponding model components. This process also facilitated translation of themes/subthemes into practical language for aid of interpretation. Researchers JG, LGW, and EB were involved in this conceptual mapping process. JG is a psychology student with an interest in research, health psychology, and wellness-promoting behaviour change, however, has no personal or professional background with palliative care. LGW has a professional background in health behaviour change, and personal and research experience in palliative care. EB has a professional background in health behaviour change, however has no prior personal or professional affiliation with palliative care.

Results

Participant demographics are detailed in Table 1. The majority of respondents were aged 25–64 years of age, were female, of a white ethnic group, and were living with a partner or spouse. A small proportion were living with a chronic physical condition (18%), a mental health condition (9%), and/or a disability (14%). Over half declared that they identified as non-religious, although almost all reported that they were raised under a certain religion. Most participants were educated to at least graduate level and a small number had migrated to Northern Ireland (the majority of which had resided in NI for more than 15 years).

Barriers to communication about death and dying

Three overlapping themes were constructed for the question surrounding barriers: 'Apprehension at navigating conversations'; 'Emotional responses to death talk'; and 'Unacceptance of death talk in different social contexts'. See Table 2.

Apprehension at navigating conversations

This theme relates to the challenge of talking about death with others. There was an assumption that death talk needs to occur in a supportive context and thus requires skilled communication. Participants conveyed concerns about their own ability or the ability of others to orchestrate conversations about death in a sensitive manner. This theme comprises two sub-themes: 1) Challenge of sensitively navigating conversations about death 2) Concern over ability of others to facilitate conversations about death.

Subtheme one captures the perspectives of participants who feel they lack the skills and confidence to instigate and sustain conversations about death when approached by others affected by death. These participants felt concerned about offending others, saying something inappropriate, or prompting discussion at an inappropriate time or in the wrong context. There was general apprehension about *how* death talk should take place.

> *Saying the 'wrong thing' (Participant 483, M, 65–69 years)*

> *If someone has recently experienced loss I would be cautious to raise the subject (Participant 739, F, 18–24 years).*

> *If the person is older and I don't know how comfortable, able, they are to discuss death (Participant 90, F, 45–54 years).*

Subtheme two describes the perception that other people are not always helpful in supporting conversations about death. This refers to the perceived ability of other people to instigate or host constructive discussions about issues/events related to death. Participants' often reflected that this can result in reluctance to open up to or confide in others. This is despite underlying wishes

Table 1 Participant socio-demographic characteristics ($N = 381$)

Age	**Freq (%)**
18–24	30 (7.9%)
25–34	56 (14.7%)
35–44	76 (19.9%)
45–54	86 (22.6%)
55–64	91 (23.9%)
65–69	17 (4.5%)
70–74	16 (4.2%)
75–79	6 (1.6%)
80–84	2 (0.5%)
85 +	1 (0.3%)
Gender	
Male	90 (23.6%)
Female	290 (76.1%)
Other	1 (0.3%)
Ethnicity	
White	372 (97.6%)
Pakistani	1 (0.3%)
Mixed ethnicity	5 (1.3%)
Other ethnicity	3 (0.8%)
Relationship status	
Single	75 (19.8%)
Married/partner	248 (65.4%)
Divorced	31 (8.2%)
Separated	11 (2.9%)
Widowed	14 (3.7%)
Chronic physical health condition	
Yes	68 (18.2%)
Chronic mental health	
Yes	31 (9%)
Disability	
Yes	52 (13.8%)
Religion (current)	
None	205 (53.9%)
Christian (of no/different denomination(s))	100 (26.3%)
Roman Catholic	132 (34.9%)
Non-Christian	7 (1.9%)
Religion (brought up with)	
None	44 (11.6%)
Christian (of no/different denomination(s))	195 (51.5%)
Roman Catholic	132 (34.9%)
Non-Christian	7 (1.9%)
Education	
Primary	1 (0.3%)
Secondary	70 (18.4%
Graduate	310 (81.3%)
Emigrated to Northern Ireland from another country	50 (14.9%)
(*of which*) duration of time living in Northern Ireland > 15 years	35 (10.4%)

Table 2 Barriers coding tree of themes and illustrative quotations

Theme	Subtheme	Illustrative Quotation
Apprehension at navigating conversations	Challenge of sensitively navigating conversations about death	*I don't want to sound insensitive* (Participant 249, F, 25–34 years)
	Concern over ability of others to facilitate conversations about death	*Bringing up the topic either makes others uncomfortable or dismiss it with a short "Sorry for your loss"* (Participant 847, F, 18–24 years)
Emotional responses to death talk	Conversations hindered by own emotions	*I get upset about it—don't want to make people uncomfortable* (Participant 862, F, 18–24 years)
	Perceived risk of arousing challenging emotions in others	*Fear of making others uncomfortable or upset (Participant 18, F, 35–44 years)*
Unacceptance of death talk in different social contexts	Societal norms sustain lack of integration of death talk	*It's just not done here, I am not sure why* (Participant 333, F, 35–44 years)
	Cultural beliefs can deter openness about death	*The discomfort of others regarding the topic. I am viewed as very strange for wanting to discuss "such negative topic", but it's important to me. I have a different philosophy and spirituality than those I love, which they struggle with* (Participant 398, F, 55–64 years)
	Perception that known others are unwilling to engage in death talk	*My family don't want to talk about it* (Participant 259, F, 70–74 years)
	Perception that death should only be discussed with family and close persons	*I don't like to share my personal feelings with people I am not close to* (Participant 494, F, 35–44 years)

that more helpful conversations could take place at times of need.

> *People seem at a loss for words and I feel quick to soothe them by brushing it off or minimising it. I suppose there is an awkwardness about death. (Participant 101, F, 18–24 years).*

> *If I'm caring for someone that is end of life and wishes not to talk about it. Or I perceive it to be inappropriate, I let the other person lead the conversation. Sometimes in a social context of I talk about personal bereavement I don't want to be met with pity, sometimes it's just a factual thing or sometimes it's not information I wish to share (Participant 32, F, 25–34 years).*

Emotional responses to death talk

This theme captures how personal emotions, or the perceived emotional response of others can hinder honest conversations about death. In particular, 'fear' was commonly referred to by many participants, and emotions including fear and upset are observed across each of the subthemes constructed: 1) Conversations hindered by own emotions 2) Perceived risk of arousing challenging emotions in others.

In the first subtheme, participants reflected on how their own emotional reactions to death prevented them from discussing death frankly with others. Participants worried that expressing feelings of sadness and emotional distress could result in the discomfort of others or might be perceived as inappropriate in certain contexts. Many participants also described how it is often difficult to talk to others when they are personally affected by death because expressing feelings is psychologically stressful. Participants also discussed how it 'scares' them to 'think about' death.

> *Knowing that I will cry and sometimes that's not acceptable or useful in certain scenarios (Participant 820, F, 45–54 years).*

> *It's difficult to talk about your own experiences. I had a very traumatic death of a sibling and received little support, although I'm now able to talk about it this has taken ten years to be able to (Participant 468, M, 25–34).*

> *It scares me to think about it (Participant 507, F, 35–44 years).*

Subtheme two describes participants' perceptions that talking about death can trigger challenging emotions in others, so there is an implicit assumption that death talk is more harmful than helpful. This deters individuals from initiating conversations about death. Participants felt that emotional reactions to death may differ across individuals and social contexts, which makes it difficult to recognise when these discussions are appropriate and acceptable (this links with theme three).

At times you want to avoid upsetting someone even though you know it would be good for them to talk (Participant 39, F, 45–54 years).

Many close family and friends fear death, and don't like…to talk about it openly (Participant 54, F, 55–64 years).

Getting tearful, upset, upsetting others. Making things worse. (Participant 415, F, 45–54 years).

Unacceptance of death talk in different social contexts

This theme captures how conversations about death are uncommon at a societal level, which sustains lack of acceptance within communities and social circles. The rationale for lack of acceptance relates to normative behavior, cultural diversity, and assumptions about the appropriateness of death talk. Four subthemes were identified for this theme: 1) Societal norms sustain lack of integration of death talk 2) Cultural beliefs can deter openness about death 3) Perception that known others are unwilling to engage in death talk 4) Perception that death should only be discussed with close others.

Subtheme one describes how conversations about death are not commonplace and scarcely feature in social interactions, except for in certain times and contexts, such as when a person is at the end of their life or in the case of grief. Even then, death talk is not widely or openly practiced. Death is perceived to be a negative topic and this belief is perceived to be embedded in our "*culture*" at a societal level.

It's just not done here, I am not sure why (Participant 333, F, 35–44)

I just don't think it's socially acceptable—people think you are in a bad mood or always thinking the worse if you talk about negative things such as dying (Participant 832, F, 18–24 years).

Subtheme two relates to participants' concerns about death talk causing offence or distress to people who have strong spiritual or "religious beliefs". Religious or spiritual beliefs/values may hinder social interactions about death because of perceived incongruity of perspectives. This subtheme interconnects with theme one as this relates to perceived ability to discuss death in a sensitive and respectful manner.

My family being religious while I am not and I would want different things when I die than they would expect (Participant 859, F, 25–34 years).

If it outwardly upsets the other person or if I don't know people very well. I am very aware that a lot of people have a very closed attitude to end of life due to their religious beliefs (Participant 238, F, 35–44 years).

Fear that I am making them talk about issues they are not comfortable with even though I am. Fear of insulting someone's core beliefs (Participant 328, F, 35–44 years).

The third subtheme relates to participants' beliefs that known others such as family, friends, and colleagues are often not willing to discuss death. Participants felt that death talk is not typically welcomed by others in their social circle. Rather, other people tend to avoid the subject and there was a sense that one might be regarded as "strange" for "wanting to discuss" it. It is this lack of inclination to facilitate discussions that may prevent people from opening up about death when they need to.

Other people's negative attitudes, I get shut down by some family members who find it hard to talk about (Participant 289, F, 18–24)

When the other person doesn't want to. My mum didn't want to know she was dying and wouldn't listen to any prognosis or treatment options (Participant 816, F, 35–44 years).

Subtheme four captures participants' perspectives that death talk is only acceptable when with close others such as family or professionals whom people feel close to. Participants felt that the sensitivity of the subject can restrict who they talk to about death and the contexts in which these conversations can happen. This interconnects with theme one as participants imply that trust and rapport are important prerequisites for discussions about death.

This is a personal topic which l would discuss only in particular circumstances and with particular people. Should l be in a position where health professionals are involved, l would be comfortable discussing death/dying only with a person with whom l felt at ease (Participant 732, F, 70–74 years).

Would need to be with someone close. Hard topic to discuss with an acquaintance or someone I am not close with (Participant 395, F, 35–44 years).

Facilitators to enhance communication about death and dying

Four overlapping themes were constructed for the question surrounding facilitators: 'Increasing knowledge of

the 'death system'; 'Improving interpersonal communication": Encouraging acceptance of the need for death talk'; 'and 'Groups and Individuals with ability to promote the discussion'. See Table 3.

Increasing knowledge of the 'death system'

This was a prominent theme which relates to how enhancing knowledge and increasing opportunities to build understanding about key terminology and processes surrounding dying and death would be a useful starting point to augment communication about the topic in different contexts. Three subthemes were constructed: 1) Information provision, 2) Education along the life course and 3) Experts sharing their experience.

The first subtheme information provision refers to the need to increase the quality and availability of informational resources to equip people with the basic knowledge to understand their options at the end of life and key terms/processes relating to areas such as palliative care and end of life care. This relates to tangible resources such as pamphlets and adverts tailored to different contexts and across different demographic groups.

Table 3 Facilitators coding tree of themes and illustrative quotations

Theme	Subtheme	Illustrative Quotation
Increasing knowledge of the 'death system'	Improving information provision	*Provide more information to patients and families on their rights and choices to help guide conversations so that people can decide and opt for what is best for them/what they want (Participant 36, F, 18–24 years)*
	Education along the life course	*Firstly being taught in schools. We learn about birth but not about death…. it's still treated like a taboo subject and as a result nobody is prepared for it.. (Participant 305, F, 35–44 years)*
	Experts sharing their experience	*Using similar campaigns which raised awareness of other social issues in the past. Also finding people who are willing to share stories and the facts…. carers and the professionals (Participant 82, F, 55–64 years)*
Improving interpersonal communication	Accessible communication from healthcare providers	*Health professionals be more direct when talking about death to paitents and families (Participant 324, F, 45–54 years)*
	Practical support to improve interpersonal communication skills	*Not sure, people don't know what to say. Too much emphasis on being positive when terminally ill (Participant 119, F, 45–54 years)*
	Increasing awareness of different belief systems	*Make it less medical so target the whole population on neutral footing. Ie not based on religion or beliefs but person centred and individual (Participant 32, F, 25–34 years)*
	Acknowledging individual responsibility in initiating discussions	*By each person talking to families and friends about their own feelings/wishes about dying AND (harder to do I think) asking others what their views/feelings/wishes are regarding their demise- not in general—specifically about their own case (Participant 474, F, 55–64 years)*
Encouraging acceptance of the need for death talk	Raising awareness of relevance across people and contexts	*Change attitudes by advertising how easy it can be and the benefit it is when we all know what is to happen at the end of life (Participant 71, F, 55–64 years)*
	Addressing fear surrounding discussion of death and dying	*By encouraging people to talk about their experience, take away the superstition that it's bad luck to talk about death! (Participant 158, F, 35–44 years)*
	Normalising death as a part of life	*If the topic is introduced in schools, with death being treated as a natural part of our lifecycle, a lot of the barriers and fears can be overcome (Participant 42, F, 55–64 years)*
Groups and Individuals with ability to promote the discussion		*More awareness, news programmes, newspaper articles, social media* etc. *(Participant 6, F, 65–69 years)*

Provide more information to patients and families on their rights and choices to help guide conversations so that people can decide and opt for what is best for them/what they want (Participant 36, F, 18–24 years).

I think that although in different social and different backgrounds, the topic of death is viewed differently, hence making a generalised fact sheet or 'black and white' explanation void. (Participant 79, F, 25–34).

In subtheme two, participants described the '*taboo*' around discussion of death and dying as a social construct which develops across the life course, with opportunity to normalize discussion through '*early*' intervention. Participants stressed the importance of embedding discussion with children and adolescents into formalized curricula within primary and secondary education, towards achieving parity with '*career advice or sexual care*'. Several developmentally appropriate topics were suggested, with need for discussion on grief and loss identified for younger children.

I feel death should be talked about more openly with children from a young age and it should not be a taboo subject that we hide from them. This should happen in the home and in schools. This will help prepare them should they face bereavement as a child or an adult. Having this knowledge may reduce the unavoidable shock and grief that individuals have to deal with at some stage of the life-course (Participant 214, F, 45–54 years).

Start earlier, include health and well-being on a school curriculum that includes issues related to death and dying—and life. Organ donation is important in its own right and also is a doorway into conversations about mortality (Participant 80, M, 55–64).

Although the contribution of formalized education was discussed in relation to schools and universities, the role of 'education' as empowering rather than simply information-provision (as in subtheme one) was frequently described in reference to adults. A key emphasis was placed on emotional preparation across the life course, in terms of bereavement at all stages and with advance care planning cited for older adults. The need for more "*public discussion*" was described, taking the form of workshops or seminars. Participants emphasized the need for there to be ownership from organisations perceived to be experts in this area (medical charities provided as examples), and the opportunity to harness existing communities such as workplaces to embed discussion.

To remove the fear and negativity around death and dying, the subject needs to be living outside where the public live (Participant 716, M, 70–74 years)

In subtheme three there is the perception of 'privileged knowledge' existing in relation to death and dying, and the need for 'experts' across various sectors to act as knowledge brokers towards sharing process and experience-based knowledge with the aim of addressing the "*mysteries*", "*myths*" and "*uncertainties*". The importance of fostering realistic expectations about end of life care was emphasized.. A diverse range of expertise was recognized, including those working in healthcare, funeral services, finance, and individuals with lived experience of the death system.

More public discussion. Encouraging health care professionals in particular to speak without fear about the processes they participate in (Participant 385, M, 65–69 years)

Using similar campaigns which raised awareness of other social issues in the past. Also finding people who are willing to share stories and the facts….carers and the professionals. (Participant 82, F, 55–64).

Improving interpersonal communication

This theme raises the importance of compassionate and person-centered communication about the topic of death and dying and provides a sense of what aspects of communication are especially important, why these are important, and who should instigate conversations about death and dying. Four subthemes were identified: 1) Accessible communication from healthcare providers, 2) Practical support to improve communication skills, 3) Increased awareness of individual differences, 4) Acknowledging individual responsibility in initiating early discussions.

Subtheme one describes the need for "*open and caring*" communication from healthcare professionals in respect to advance care planning. There was a general perception that a culture change is needed regarding communication about death and dying in health contexts, whereby optimising access to specialist palliative care and embedding palliative care approaches within generalist health and social care structures will facilitate "*earlier*" and more "*routine*" conversations. The importance of training and support for healthcare professionals was also described. The importance of getting to know the patient through provision of anticipatory care to ensure future care is person-centred was emphasised.

In most circumstances death & dying are anticipated, usually in a healthcare setting. This presents an opportunity for healthcare professionals to broach the subject with their patients and families. I feel that this should become a more 'routine' conversation in clinical care. It is too often discussed at a very late stage which may only add to a sense of stress and reduce the time available for careful reflection. This would require something of a culture change in healthcare, adequate training in communication could help this. (Participant 817, M, 25–34)

By health professionals setting the bar and talking about it in an open and caring way (Participant 18, F, 35–44 years)

Subtheme two describes the belief that increased interpersonal support and communication skills training for people across demographic groups could increase an individual's capacity to facilitate death talk. This relates to supporting individuals to have more 'open and honest' discussions, including the need to avoid the use of euphemisms around death or being overly positive. Providing advice on "*conversation openers*" was recommended, with organ donation cited as a useful anchor to initiate conversations, including discussion into different types of deaths. Participants emphasized a need for skill development around how to compassionately listen when discussion is instigated by others on death and loss, with recognition this is a "*learned skill*". A particular focus was placed on developing an awareness of helpful and unhelpful responses, with the latter serving to limit in depth discussion.

A public health campaign promoting awareness of why we need to openly talk about death. Workshops e.g., for parents to learn how to talk to children about death. Classes in schools that contain an element of discussion about death (Participant 367, F, 45–54 years).

Teach younger people how to discuss sympathetically as this is learned skill (Participant 406, M, 55–64)

Subtheme three suggests that to facilitate a supportive conversation about death and dying it may be helpful to avoid dogmatic topics which may arouse conflict and discomfort. Rather, there is emphasis on the need to talk about death and dying from the perspective of "*human understanding*", to enable participation of people from diverse belief systems. Emphasis was placed on religious organisations as having ownership of discussion around death and dying, with a focus on the afterlife rather than end of life.

By normalising it. Making it ok for dying people to talk about death. Children be informed maybe in a non-religious way. Acceptance of the pain of death alongside the inevitability. Maybe it'd help people be more grateful of life (Participant 496, F, 45–54 years).

By encouraging honest discussion without moral or religious judgement (Participant 785, F, 45–54 years)

Subtheme four relates to the need for individuals to acknowledge that they have a personal role in initiating or engaging in conversations about death and dying, however challenging. Such conversations were perceived to begin at the familial level, with a need for open discussion around wishes and feelings towards death and dying. The importance of not excluding younger family members from these discussions was emphasised, with a need for "*healthy conversations from childhood throughout adulthood*".

By each person talking to families and friends about their own feelings/wishes about dying AND (harder to do I think) asking others what their views/feelings/wishes are regarding their demise- not in general—specifically about their own case (Participant 474, F, 55–64 years)

I think we need to be brave and start the conversations with our family, especially in aspects of organ donation wishes and end of life care (Participant 10, F, 35–44 years)

Participants described how developing plans for end of life should be embedded within these supportive conversations, which need to happen early, prior to rapid decline of health in oneself or others. In addition to establishing preferences around end of life care, the opportunity for individuals to plan their own funerals and develop living wills was also articulated.

We encourage pregnant women to have birth plans so why can't we normalise the death plan (Participant 816, F, 35–44 years)

Encouraging acceptance of the need for death talk This theme explores the need to increase the acceptability of engaging in supportive conversations about death and dying, as a precursor to the other themes. Three subthemes are contained within this: 1) Raising awareness of relevance to different populations 2) Addressing fear surrounding discussion of death and dying 3) Normalise death as a natural part of life.

The first subtheme describes how it is necessary to help individuals to understand why talking about death and dying might be relevant for them, across different stages of life and diverse contexts. Recognising the relevance may promote a more open attitude towards engaging in such conversations. The need for health promotion campaigns was emphasized. Alongside this was the perception that certain deaths are seen as more socially acceptable, with other deaths more likely to not be discussed. It was described how parity is needed in changing attitudes towards the discussion of deaths relating to child/baby death, suicide, drug addiction and clinician-assisted death.

> *I feel we only talk about death after the event and not in forward planning. We need people to accept and understand that critical illness can affect us at any age (Participant 238, F, 35–44 years).*

> *Healthcare conversations about end of life should be introduced in middle age (Participant 712, F, 25–34)*

Subtheme two focuses on the need to support individuals who feel afraid to initiate or engage in discussions around death and dying. Participants described a perceived relationship between "*taking about dying and hastening death*", and an associated belief that "*if we don't talk about it, it is not going to happen*". The need to help individuals disassociate superstitious fears was emphasized. Fear is recognized as a prominent emotional barrier and thus strategies to reduce fear should be explored.

> *Not sure. It's a societal thing, people fear that by talking about it, it will somehow bring death to them (Participant 134, F, 35–44 years)*

> *By encouraging people to talk about their experience, take away the superstition that it's bad luck to talk about death! (Participant 158, F, 35–44)*

Subtheme three explores the usefulness of promoting acceptance of death and dying as a natural part of the lifecycle, not to be stigmatised but rather understood. This includes changing attitudes away from "*the belief that talking about death is morbid*" and rather encouraging society to be "*death positive*". Participants referred to death cafes as being a useful facilitator of a positive attitude to death, along with using death to facilitate a focus living meaningfully.

> *I think when you compare the polarity between birth and death of how much it is acknowledged its bizarre. Death is just as big a part of life. Yet there is zero sense of belonging or community in it. It feels like a stigma. Taboo. Keep hush. It should be as easily spoken about as a birth or even like a wedding. It's such a knee jerk reaction to cower away from it when if we could all embrace it and bring a sense of community camaraderie to it, it wouldn't be as dark and frightening (Participant 316, F, 25–34 years).*

Prevalent within this subtheme was the need to change protectionist attitudes towards discussing death and dying with children and younger family members, "*it should not be a taboo subject we hide from them*". Emphasis was placed on engaging openly and honestly with children around death, and not dismissing or explaining death is a reductionist manner. Participants also described the need for society to encourage inclusion of children within death rituals such as funerals and wakes, and to not hide serious illness or grief to normalise emotional reaction to death.

> *By not excluding children from discussing the death/funerals of elderly relatives and pets, often a way to show that death is a part of living and importantly allowing them to express their emotions (Participant 270, F, 70–74 years).*

Groups and Individuals with ability to promote the discussion

This overarching theme captures the variety of stakeholders, services, and approaches with potential to facilitate greater communication about death and dying. Sources yielded through a content-based extraction of key communicative tools/sources include: 1) Media 2) The Arts 3) Experts 4) Service Users 5) Third Sector 6) Healthcare providers 7) Individuals 8) Schools 9) Policy makers 10) Researchers. The capacity to endorse greater communication about the topic broadly relates to utilizing a range of vessels/resources to (considering the issues raised in previous themes) educate individuals e.g. schools or charities providing workshops/talks, raise awareness e.g. emotive social media posts/images, normalize e.g. open discussions instigated within families, addressing challenging emotions like fear through theatre/film or service users sharing their experiences. Within this theme, the role of policy makers is also discussed, suggesting that there is potential to augment communication about death and dying across various levels of society.

Integrated findings

As illustrated by Fig. 1, the barriers and facilitators when integrated can be conceptualised to relate broadly to interpersonal communication, actors and systems with a role in supporting change, knowledge about death and dying, and integrating death talk in everyday life. This illustrates core constructs which interventions can be

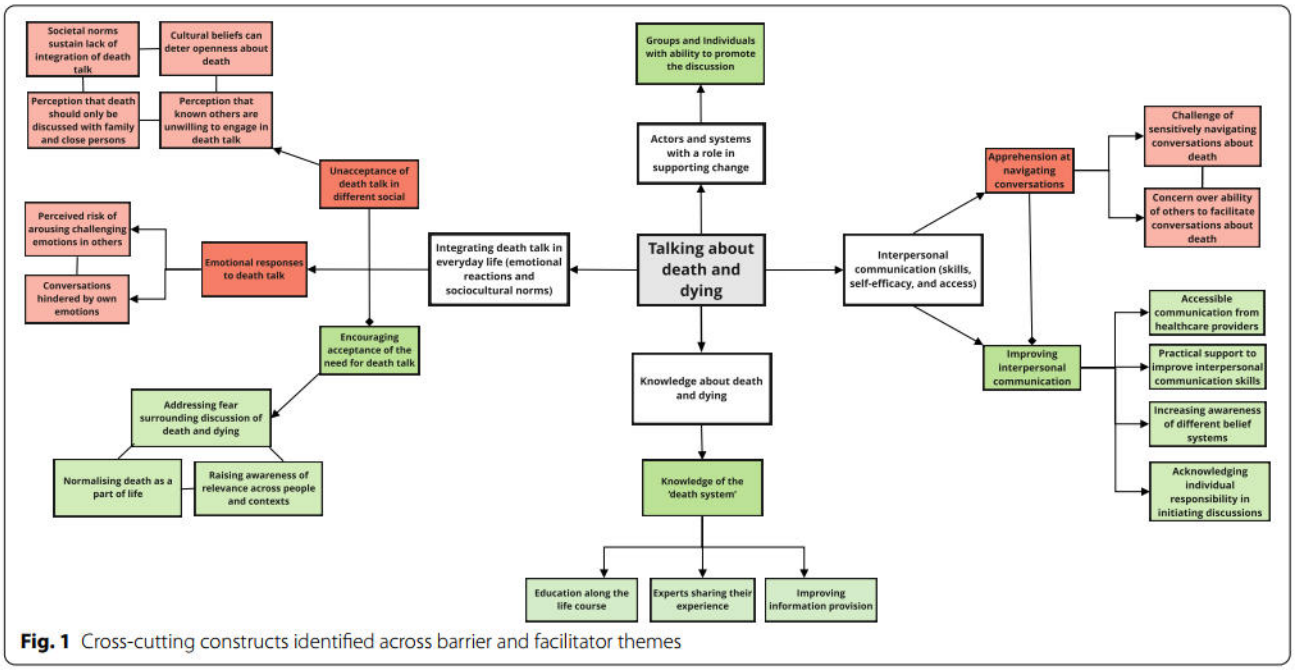


Fig. 1 Cross-cutting constructs identified across barrier and facilitator themes

designed to target, by framing the perceived barriers to talking about death and dying in the context of prospective solutions to mitigating these.

Barriers and facilitators mapped to Behaviour Change Theory

The barriers and facilitators to talking about death and dying mapped to most constructs within the COM-B and TDF. Table 4 presents the barriers and facilitators translated into a series of descriptions which are aligned with conceptually relevant COM-B and TDF constructs.

Relevant constructs for both barriers and facilitators include 'Psychological Capability' under the TDF domains 'knowledge' and 'skills', where facilitators described strategies to address the knowledge and skills barriers identified. 'Social Opportunity', within the TDF domain 'social influences', was also relevant, where facilitators described strategies to adjust existing social norms (i.e. increasing opportunities to normalize discussion). Another pertinent construct was 'Reflective Motivation', within the TDF domains 'social/professional role/identity' and 'beliefs about consequences'. Barriers described apprehension about whether social role/identity restricted death talk and causing discomfort as result of death talk. Whereas, facilitators described ways to enhance professional responsibility in health contexts and increasing perception of the benefits and relevance of discussions about death across the lifecycle. Related to this, the construct 'Physical Opportunity' was mapped to facilitators within the TDF domain 'Environmental Context and Resources', and described the infrastructural change needed in health systems to increase opportunities for death talk. Lastly, 'Emotions', under the construct 'Automatic Motivation' was also relevant, where facilitators described ways to address challenging emotions and the perception of arousing challenging emotions in others.

Less relevant constructs appeared to be 'Physical Capability' (COM-B), several of the TDF domains under 'Psychological Capability' (Memory, Attention and Decision Processes & Behavioural Regulation), one domain under 'Reflective Motivation' (Goals), and two domains under 'Automatic motivation' (Optimism and Reinforcement).

Discussion

This study contributes to an emergent evidence towards understanding the barriers and facilitators to talking about death and dying for the general population. Previous research identifies several barriers including lack of knowledge of the death system [51], fear/distress associated with thinking about death and dying [52] and difficulty engaging others in death talk or fear of upsetting others [53]. An aligned Welsh study [47] conducted at a similar period of time to the current study identified several levels of barriers, including social perception and practice (e.g. death as a societal 'taboo'), lack of opportunities (e.g. perception of no family & friends to talk about this with) and support and personal emotions and values (e.g. concern over causing distress). The Welsh study also identified several facilitators, such as enhancing

Table 4 Barriers and facilitators mapped to the COM-B and TDF

COM-B Component	TDF Domain	Barriers	Facilitators
Psychological Capability	Knowledge	Lack of understanding of how to engage in death talk in a way that is helpful and supportive (*overlaps with apprehension at navigating conversations*) Uncertainty about when and with whom it is appropriate to engage in death talk (*overlaps with social role/responsibility*)	Increase quality and availability of tangible information resources (tailored to different contexts & groups) to facilitate understanding of options at the end of life and key terms/ processes Experts across various sectors to share process and experience-based knowledge of the death system (*overlaps with social influences*) Provide education along the life course to empower and emotionally prepare individuals
	Skills	Lacking the interpersonal skills to facilitate constructive (i.e. sensitive and culturally respectful) conversations about death (*overlaps with beliefs about capabilities*)	Increase interpersonal support and communication skills training for people across demographic groups to facilitate death talk Support individuals to talk about death and dying in a way which enables participation of people from diverse belief systems
	Memory, Attention and Decision Processes	-	-
	Behavioural Regulation	-	-
Physical Capability	Skills	-	-
Social Opportunity	Social Influences	Perception that other people are unwilling to engage in constructive conversations around death Death is not commonly discussed within NI culture and religious diversity invites sensitivity toward death talk	Normalize death talk through early intervention by embedding discussion with children and adolescents within formal education and the family (*overlaps with intentions*) Harness existing communities such as workplaces to embed discussion such as death cafes
Physical Opportunity	Environmental Context and Resources	Conversations about death with close others occurring at a late stage and this timing issue is a challenge	Optimise access to specialist palliative care and embed palliative care approaches within generalist health and social care structures to facilitate earlier and more routine conversations
Reflective Motivation	Social/Professional Role and Identity	Death talk is perceived to be only appropriate within the context of families or with professionals	Encourage individuals to acknowledge they have a personal role in initiating and engaging in conversations around death and dying (*overlaps with intentions*) Provide training and support for healthcare professionals to have more routine ACP conversations (*overlaps with skills*)
	Beliefs about Capabilities	Individuals believe they are not capable of discussing death in a helpful way (overlaps with skills	Provide guidance on 'conversation openers' to facilitate individuals to instigate conversations
	Beliefs about Consequences	Individuals believe that discussing death will result in social and/or personal discomfort (*psychosocial repercussions*)	Help individuals to understand why talking about death and dying might be relevant to them, at different stages in life Help individuals to understand the benefits of developing plans for end of life at an early stage, within supportive conversations Help individuals to develop a positive attitude to death, by using death to facilitate a focus on living meaningfully
	Intentions	Assumption that others generally are not willing to/ do not want to discuss death	Help individuals to recognize that others wish to have conversations around death and dying
	Goals	-	-

Table 4 (continued)

COM-B Component	TDF Domain	Barriers	Facilitators
Automatic Motivation	Optimism	-	-
	Reinforcement	-	-
	Emotion	Anticipated emotional reactions hinder conversation about death *(unpleasant emotions underpin social and personal barriers)*	Help individuals to disassociate superstitions and to address fear around talking about death and dying

acceptance of death as a part of life and using a public health approach to engage the public across the life-course. The current study establishes that these barriers are pertinent for community-dwelling adults in Northern Ireland, and provides a rich understanding within this regional context. Several novel barriers to talking about death and dying were also identified, including a focus on interpersonal communication skills and cultural beliefs. The identification of facilitators to provide a more multi-dimensional understanding of the drivers of this behaviour was also a novel contribution of this study, with a previous lack of prior attention in the research literature [47].

The current study would suggest that societal norms place boundaries on the perceived opportunities for death talk, with respondents believing that these conversations should only take place within families and in particular circumstances. This is a significant constraint when individuals believe family members are not willing to engage in death talk, as is similarly reported by previous UK research [53]. There is indication of death talk as potentially a 'limited taboo' [54], with not 'society' per say but rather particular subgroups finding talk of death and dying challenging. It is unclear whether this relates to death as a psychological taboo, or rather suggests conversational embarrassment in engaging in death talk [55]. Indeed, a prominent theme in the current study describes respondent's concern around the acceptability of emotional expression during these conversations with family and friends. This suggests that increasing awareness and accessibility of safe spaces such as Death Cafes for gentle discussion of death and dying with wider community members is valuable [56]. There is a dearth of formal evaluation on such initiatives [56], but conceptually the aim of Death Cafes includes supporting individuals to express emotion that may not feel able to do elsewhere, another key barrier reported in this study. There is suggestion that engagement with Death Cafes in the UK is currently dominated by middle-aged women working in healthcare [57], with a need to consider how such initiatives may be optimised to engage 'hidden publics' such as young people and men.

The perception that others are unwilling to engage in death talk relates to a key facilitator on the importance of normalising discussion of death and dying. Towards this goal, a life-course approach to discussing death and dying was suggested, and similarly proposed in terms of the need for education on the death system. Educational settings were cited as an opportunity to engage children and young adults, embedded within the context of life skills (i.e., equated to 'sex education' by respondents). Although there is a dearth of research on children's perception of death, Paul [58] proposes a model of 'death ambivalence' where children are both death avoidant and death facing. The avoidance of death was however largely a result of the social domains the children were part of (family & education), in addition to wider cultural norms of what it means to be a child. There is an openness and desire for information and discussion of death from children [58], and recent research in Spain would indicate parents are favourable about inclusion of death education in their children's schooling [59]. Recent research in Northern Ireland [60] also suggests value in integrating education on the death system in young adults' university education, where a high level of awareness but lack of knowledge around palliative care is reported.

Respondents discussed concern about their interpersonal communication skills, which referred to both the respondent's perception of their own skill and their perception of the skill of others to engage in meaningful conversations about death and dying. Although there was an identified need to encourage individual responsibility in initiating these conversations, this theme largely centred around equipping interested individuals with the 'tools' for engagement. There has been a focus on developing evidence-based peer-led ACP facilitator training programmes [61], involving either peers or lay volunteers. This has involved facilitating ACP conversations and advance care directive completion, and provision of ACP education, training, and support. The majority of this training is focused on enabling volunteers to facilitate ACP conversations with older adults or clinical populations [61], however there is an evidence-base on which to inform supportive programmes for individuals in the community to facilitate conversations with close persons. There are also existing public-facing initiatives in this area which could be highlighted as part of a larger programme of support, e.g., the 'Conversation Starter Kit' [62]. For future generations, a life-course approach to discussing death and dying in early education may negate the need for formal programmes if individual self-efficacy around having these important conversations is improved through exposure.

Respondents in this study discussed concern about death talk causing offence/distress to people with strong spiritual or religious beliefs, which hinders death talk because of perceived incongruity of perspectives. This finding may be particularly pertinent to Northern Ireland, a post-conflict society in which religion can form an important part of individual's social identity which influences their attitudes towards 'outgroup' members and may have resulted in heightened sensitivity [63]. There is also however relevance to the UK population more broadly, with an increasingly multi-cultural society [64] and adults identifying as non-religious [65], resulting in communities which are increasingly diverse in relation to

spiritual or religious beliefs. Increasing awareness of different belief systems was reported as a facilitator in the current study and would appear an important component in interpersonal communication skills training for contemporary society.

Despite the majority of UK adults reporting being comfortable discussing death and dying with family and friends [20], recent reports would indicate only a minority have engaged in a conversation about their end of life wishes with others [10]. Health behaviour change theory includes the COM-B model [33] which can help in identifying the sources of a behaviour, to inform behaviour change interventions. Adults report being comfortable discussing death and dying with family and friends [20] could refer to being willing to have these conversations (*COM-B; motivation*), confident in having these conversations (*COM-B; capability*) or able to have conversations in prescribed circumstances (*COM-B; opportunity*). The COM-B model recognises the complexity in behaviour change and proposes that motivation, opportunity, and capability all need to be present in order for an individual to engage in a behaviour. The current study identifies several barriers and facilitators to talking about death and dying, which map to the majority of the COM-B components, and furthermore the TDF [34]. This suggests that in attempting to encourage community-dwelling adults to change their behaviour towards engaging more in death talk, it is likely that multiple complex interventions are needed, supported by policy level directives. The sources of behaviour identified in the current study will be relevant to community-dwelling adults in Northern Ireland, but alignment with previous research indicates generalisability to the wider UK. As a research area in its infancy, it may be useful to consider how existing initiatives map on to the COM-B model to identify mechanisms of change which may influence outcome.

There are few 'upstream' interventions to encourage conversations about death and dying among community members in the general population. Abba and colleagues [66] in their systematic review identified 5 studies, with only one study [67] developed to directly encourage individuals to discuss death and dying with family and friends. The evidence-base in this area is limited in both size and quality [66], however there is indication that passive methods of providing information (e.g., public lectures) are unlikely to be as effective as participatory approaches. Indeed, the need for education is a facilitator cited in the current study, but only addresses one component (*COM-B; capability*) of the multi-component approach needed. There are various examples of more experiential initiatives taking place in practice, yet few are formally evaluated. There is however promising evidence from evaluation of such initiatives in recent years, which may be more likely to address multiple COM-B components. An example is *the Heart of Living and Dying* in Northern Ireland [68], a supported group conversation where community members are invited to reflect on what matters to them in living and dying to begin to plan ahead. These novel initiatives are reflective of the need for innovation in this area [56], with a variety of structural barriers to community empowerment [69]. The current study identifies a variety of stakeholders, services, and approaches to facilitate greater communication about death and dying which may inform further innovation. Beyond intervention approaches at community-level, behavioural economics may inspire population-level interventions which are more efficient and economical, and based on strategies already utlilised by UK public health governenments e.g. the Behavioural Insights Team (a UK-based global social purpose organization) [70]. Interventions rooted in behavioural economics can be applied to public health policy and population-level programmes, and typically focus on restructuring social and physical environments to *gently* endorse (or 'nudge') health-promoting behaviour [70]. General examples include reducing the cognitive burden of health information (e.g. simplication of information on advance care planning to reduce decision fatigue), making the default option favour the desired behaviour (death literacy a part of the school cirriculum), and priming the desired behaviour via a relevant and familiar source (e.g. opening up a conversation around death, dying or loss is modelled/ captured in an episode of a popular drama series). Interventions based on this approach target drivers of behaviour such as emotions and impulses, habits, and social norms *indirectly* [70]. Behavioural economics therefore presents a potentially powerful toolkit to influence decision-making around communication about death and dying by redesigning the choice architecture. Evidence surrounding the effectiveness of interventions based on behavioural ecominics in health contexts in general is lacking and thus we lack guidance on the appropriate design and evaluation of such interventions [71]. However, the identification of drivers of communication about death and dying, particularly those which are relevant to behavioural economics approaches (e.g. via indirect targeting of social norms, habits, and emotions), is a useful first step to informing the design of population-level behavioural 'nudges'.

Strengths and Limitations

This is one of a small number of studies to examine the drivers of why community-dwelling adults do not engage conversations around death and dying. This study represents a ground-up approach to identifying barriers to death talk, and uniquely identifies facilitators to present a

more holistic understanding of the sources of behaviour. A novel application of health behaviour change theory is provided, which adds support to the growing utility of this approach in palliative and end of life care [e.g. 32;35–37]. This is the first step of systematically developing an evidence and theory-based intervention using the Behaviour Change Wheel [33]. The barriers and facilitators aligned to COM-B and TDF domains may be further mapped to intervention and policy functions, in using the BCW to systematically develop evidence and theory-based behaviour change interventions. The current study also has several limitations. A convenience sample was recruited via social media and is not representative of the population of the Northern Ireland, for example with an over-representation of respondents identifying as female and who have completed a higher education degree. Individuals without digital literacy skills would have been excluded. The sample does however include a largely non-clinical population, therefore addressing the need for more research with the full population of interest, including younger adults [14]. A survey design with two open-ended questions were used to enable recruitment of a large sample, however it is acknowledged that interviews or focus groups may have resulted in richer data. It also must be recognised that in developing behaviour change interventions, it is the recommended to specify the behaviour according to the AACTT framework; Action, Actor, Context, Target, and Time [72]. The behaviour in this study (*talking about death and dying*) was not specified in this level of detail, and so is reflective of broad drivers of the behaviour for the population across different contexts, similar to the application of behaviour change theory to implementation of ACT in a recent systematic review [37]. It is acknowledged that this study adopted a 'wide-angle lens' to exploring the topic at a population level, and so recommendations pertaining to population subgroups cannot be made, though are suggested in the narrative. A related limitation is that the focus of the study was on self-reported barriers and facilitators of death talk, without focus on individual differences which have been associated with not having discussed end-of-life wishes in previous research [10] such as male sex, young age, not being born in the UK or owning one's own residence. This underlines the importance of value of research to identify modifiable risk factors in key subgroups of the population. The focus of the current study is one UK region (Northern Ireland), and so the findings are most relevant for tailoring interventions for this population. Although similarity with previous UK-based research would indicate generalisability, future research directly focused on identifying barriers and facilitators to talking about death and dying is needed to confirm if these drivers are relevant for the wider UK population.

Conclusions

The current study identified barriers and facilitators to death talk in Northern Ireland, reflecting knowledge about death and dying, the integration of death talk into everyday life, interpersonal communication, and actors and systems with a role in supporting change. A consideration of why we are not having conversations around death and dying with those in our communities has never been as pertinent [73]. Not only is embedding a meaningful conversation around death in the community important for achieving a good death across different circumstances, but a greater awareness of death and physical distancing restrictions from the COVID-19 pandemic may have led to individuals reflecting more on their core values. Reflecting on values, preferences and goals is a core component of ACP [8], suggesting a timeliness for community-level public health interventions to encourage death talk among the public. Towards this goal, the findings from the current study provide a vital understanding of the key drivers of this public health behaviour. This novel understanding is ready to be applied by other researchers to systematically develop evidence and theory-based behaviour change interventions using the BCW, towards increasing individual engagement in death talk. It is possible that the COVID-19 pandemic will have influenced some of the identified barriers and facilitators, for example, for a subgroup of individuals there may now be more social opportunity for death talk. A follow-up study is currently underway to determine if and how this period of mass bereavement has impacted on community-led conversations about death and dying.

Acknowledgements
We would like to thank colleagues at Marie Curie Northern Ireland for their input in optimizing the content of the survey for the regional context.

Authors' contributions
All authors contributed to the conception and design of the work, LG-W, EB & JG the data collection and analysis, LG-W & EB the drafted the work, and all authors approved the submitted version and agree to be personally accountable for the author's own contributions and to ensure questions related to accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature. All authors read and approved the final manuscript.

Funding
This research was supported by an undergraduate research assistantship award from the British Psychological Society and a studentship award from the School of Psychology, Queen's University Belfast.

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study was approved by the QUB EPS Faculty Research Ethics Committee (EPS19_04), and conducted in accordance with the Declaration of Helsinki. Participants completed an informed consent statement prior to completion of the survey and provided informed consent for use of their data again at survey completion.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Author details

[1]Centre for Improving Health-Related Quality of Life, School of Psychology, Queen's University Belfast, Belfast, UK. [2]Marie Curie Palliative Care Research Centre, Cardiff University, Cardiff, UK. [3]Marie Curie Northern Ireland, Belfast, UK.

Received: 17 September 2021 Accepted: 19 April 2022
Published online: 06 May 2022

References

1. NISRA. 2018-based Population Projections for Northern Ireland. 2019 [cited 2021 April 19]. Available from; https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/NPP18_Bulletin.pdf
2. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, Murtagh FE. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med. 2017;15(1):1.
3. Sleeman KE, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, Gomes B, Harding R. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. Lancet Glob Health. 2019;7(7):e883–92.
4. DoH. End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life, London. 2008 [cited 2021 April 19]. Available from; https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf
5. DHSSPS. Living Matters: Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland, Belfast, 2010 [cited 2021 April 19]. Available from; https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/living-matters-dying-matters-strategy-2010.pdf
6. Scottish Government. Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland, Edinburgh, 2008 [cited 2021 April 19]. Available from; https://www.cen.scot.nhs.uk/wp-content/uploads/2017/01/LivingDyingWell.pdf
7. McCorry NK, O'Connor S, Leemans K, Coast J, Donnelly M, Finucane A, Jones L, Kernohan WG, Perkins P, Dempster M. Quality indicators for palliative day services: a modified Delphi study. Palliat Med. 2019;33(2):197–205.
8. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, Matlock DD, Rietjens JA, Korfage IJ, Ritchie CS, Kutner JS. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. J Pain Symptom Manage. 2017;53(5):821–32.
9. Brinkman-Stoppelenburg A, Rietjens JA, Van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. Palliat Med. 2014;28(8):1000–25.
10. Gallagher J, Bolt T, Tamiya N. Advance care planning in the community: factors of influence. BMJ Supportive & Palliative Care Published Online First. 2020. https://doi.org/10.1136/bmjspcare-2020-002221.
11. McIlfatrick S, Slater P, Beck E, Bamidele O, McCloskey S, Carr K, Muldrew D, Hanna-Trainor L, Hasson F. Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study. BMC Palliat Care. 2021;20(1):1–1.
12. Fried TR, Redding CA, Robbins ML, Paiva AL, O'Leary JR, Iannone L. Development of personalized health messages to promote engagement in advance care planning. J Am Geriatr Soc. 2016;64:359–64.
13. Prince-Paul M, DiFranco E. Upstreaming and normalizing advance care planning conversations—a public health approach. Behav Sci. 2017;7(2):18.
14. Sallnow L, Tishelman C, Lindqvist O, Richardson H, Cohen J. Research in public health and end-of-life care–building on the past and developing the new. Progress in Palliative Care. 2016;24(1):25–30.
15. Kellehear A. Health-promoting palliative care: developing a social model for practice. Mortality. 1999;4(1):75–82.
16. Bellamy G, Gott M, Waterworth S, McLean C, Kerse N. 'But I do believe you've got to accept that that's what life's about': older adults living in New Zealand talk about their experiences of loss and bereavement support. Health Soc Care Community. 2014;22(1):96–103.
17. Mills J, Rosenberg JP, McInerney F. Building community capacity for end of life: an investigation of community capacity and its implications for health-promoting palliative care in the Australian Capital Territory. Crit Public Health. 2015;25(2):218–30.
18. Noonan K, Horsfall D, Leonard R, Rosenberg J. Developing death literacy. Progress in Palliative Care. 2016;24(1):31–5.
19. Leonard R, Noonan K, Horsfall D, Psychogios H, Kelly M, Rosenberg J, Rumbold B, Grindrod A, Read N, Rahn A. Death literacy index: a report on its development and implementation. 2020 [cited 2021 April 19]. Available from; https://researchdirect.westernsydney.edu.au/islandora/object/uws:56211/datastream/PDF/view
20. Dying Matters Coalition. Public opinion on death and dying. 2016 [cited 2021 April 19]. Available from; https://www.dyingmatters.org/sites/default/files/files/NCPC_Public%20polling%2016_Headline%20findings_1904.pdf
21. Brooks LA, Manias E, Nicholson P. Barriers, enablers and challenges to initiating end-of-life care in an Australian intensive care unit context. Aust Crit Care. 2017;30(3):161–6.
22. Blackwood DH, Walker D, Mythen MG, Taylor RM, Vindrola-Padros C. Barriers to advance care planning with patients as perceived by nurses and other healthcare professionals: a systematic review. J Clin Nurs. 2019;28(23–24):4276–97.
23. Prod'homme C, Jacquemin D, Touzet L, Aubry R, Daneault S, Knoops L. Barriers to end-of-life discussions among hematologists: A qualitative study. Palliative medicine. 2018;32(5):1021–9.
24. Greutmann M, Tobler D, Colman JM, Greutmann-Yantiri M, Librach SL, Kovacs AH. Facilitators of and barriers to advance care planning in adult congenital heart disease. Congenit Heart Dis. 2013;8(4):281–8.
25. Travers A, Taylor V. What are the barriers to initiating end-of-life conversations with patients in the last year of life? Int J Palliat Nurs. 2016;22(9):454–62.
26. Van den Heuvel LA, Hoving C, Schols JM, Spruit MA, Wouters EF, Janssen DJ. Barriers and facilitators to end-of-life communication in advanced chronic organ failure. Int J Palliat Nurs. 2016;22(5):222–9.
27. Bernard C, Tan A, Slaven M, Elston D, Heyland DK, Howard M. Exploring patient-reported barriers to advance care planning in family practice. BMC Fam Pract. 2020;21:1–9.
28. Kaplan LM, Sudore RL, Arellano Cuervo I, Bainto D, Olsen P, Kushel M. Barriers and solutions to advance care planning among homeless-experienced older adults. J Palliat Med. 2020;23(10):1300–6.
29. Llewellyn R, Jaye C, Egan R, Cunningham W, Young J, Radue P. Cracking open death: death conversations in primary care. J Prim Health Care. 2016;8(4):303–11.
30. MRC. Developing and evaluating complex interventions. 2019 [cited 2021 April 19]. Available from; https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/
31. Demiris G, Parker Oliver D, Capurro D, Wittenberg-Lyles E. Implementation science: implications for intervention research in hospice and palliative care. Gerontologist. 2014;54(2):163–71.
32. Kubi B, Enumah ZO, Lee KT, Freund KM, Smith TJ, Cooper LA, Owczarzak JT, Johnston FM. Theory-Based Development of an Implementation Intervention Using Community Health Workers to Increase Palliative Care Use. J Pain Symptom Manage. 2020;60(1):10–9.
33. Michie S, Van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci. 2011;6(1):1–2.
34. Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. Implement Sci. 2012;7(1):1–7.
35. Biondo PD, King S, Minhas B, Fassbender K, Simon JE. How to increase public participation in advance care planning: Findings from a World

Café to elicit community group perspectives. BMC Public Health. 2019;19(1):1–1.
36. Peck V, Valiani S, Tanuseputro P, Mulpuru S, Kyeremanteng K, Fitzgibbon E, Forster A, Kobewka D. Advance care planning after hospital discharge: qualitative analysis of facilitators and barriers from patient interviews. BMC Palliat Care. 2018;17(1):1–1.
37. Combes S, Nicholson CJ, Gillett K, Norton C. Implementing advance care planning with community-dwelling frail elders requires a system-wide approach: an integrative review applying a behaviour change model. Palliat Med. 2019;33(7):743–56.
38. James Lind Alliance. Palliative and end of life care priority setting partnership. 2015 [cited 2021 April 19]. Available from; https://www.mariecurie.org.uk/globalassets/media/documents/research/PeolcPSP_Final_Report.pdf
39. Nelson, A. Beyond the questions- shared experiences of palliative and end of life care. 2016 [cited 2021 April 19]. Available from; https://amrcopenresearch.org/documents/2-15
40. Kirshbaum MN, Carey I, Purcell B, Nash S. Talking about dying and death: a focus group study to explore a local community perspective. Nursing Reports. 2011;1(1):29–34.
41. Paul S, Sallnow L. Public health approaches to end-of-life care in the UK: an online survey of palliative care services. BMJ Support Palliat Care. 2013;3(2):196–9.
42. Abbey E, Craig C, Mayland CR. General practitioners' perceptions of compassionate communities: a qualitative study. BMC Palliat Care. 2020;19(1):1–8.
43. Braun V, Clarke V, Boulton E, Davey L, McEvoy C. The online survey as a qualitative research tool. Int J Soc Res Methodol. 2020;16:1–4.
44. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res. 2004;6(3): e34.
45. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
46. British Psychological Society. Ethics Guidelines for Internet-mediated Research. INF206/04.2017. Leicester: 2017 [cited 2021 April 19]. Available from: https://www.bps.org.uk/news-and-policy/ethics-guidelines-internet-mediated-research-2017
47. Islam I, Nelson A, Longo M, Byrne A. Before the 2020 Pandemic: an observational study exploring public knowledge, attitudes, plans, and preferences towards death and end of life care in Wales. BMC Palliat Care. 2021;20(1):1–12.
48. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
49. Korstjens I, Moser A. Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. European Journal of General Practice. 2018;24(1):120–4.
50. McGowan LJ, Powell R, French DP. How can use of the Theoretical Domains Framework be optimized in qualitative research? A rapid systematic review. Br J Health Psychol. 2020;25(3):677–94.
51. McCarthy J, Weafer J, Loughrey M. Irish views on death and dying: a national survey. J Med Ethics. 2010;36:454–8. https://doi.org/10.1136/jme.2009.032615.
52. UK IRfE: How to Have a Good Death - General Public. UK: ICM Research; 2006.
53. Lloyd-Williams M, Kennedy V, Sixsmith A, Sixsmith J. The end of life: a qualitative study of the perceptions of people over the age of 80 on issues surrounding death and dying. J Pain Symptom Manage. 2007;34:60–6.
54. Walter T. Modern death: taboo or not taboo? Sociology. 1991;25(2):293–310.
55. Kellehear A. Are we a 'death-denying'society? A sociological review. Soc Sci Med. 1984;18(9):713–21.
56. Richards N, Koksvik GH, Gerson SM, Clark D. The global spread of death café: a cultural intervention relevant to policy?. Social Policy and Society. 2020;19(4):553–72.
57. Green L, Daley A, Ward A, Wilcock T. P-34 If death cafes are the answer, what is the question? BMJ Support Palliat Care. 2016;6:A21.
58. Paul S. Is death taboo for children? Developing death ambivalence as a theoretical framework to understand children's relationship with death, dying and bereavement. Child Soc. 2019;33(6):556–71.
59. de la Herrán GA, Herrero PR, Serrano Manzano BF. Do parents want death to be included in their children's education? Journal of Family Studies. 2020;11:1–8.
60. Mallon A, Slater P, Hasson F, Casson K, McIlfatrick S. What do young adults know about palliative care? A cross-sectional survey Public Health. 2021;1(191):78–84.
61. Sellars M, Simpson J, Kelly H, Chung O, Nolte L, Tran J, Detering K. Volunteer involvement in advance care planning: a scoping review. J Pain Symptom Manage. 2019;57(6):1166–75.
62. IHI. Your conversation starter kit: How to talk about what matters to you and have a say in your health care. 2021 [cited 2021 April 19]. Available from; https://theconversationproject.org/wp-content/uploads/2020/12/ConversationStarterGuide.pdf
63. O'Driscoll D, Taylor LK, Dautel JB. Intergroup resource distribution among children living in segregated neighborhoods amid protracted conflict. Peace and Conflict: Journal of Peace Psychology. 2018;24(4):464.
64. Rees P, Wohland P, Norman P, Boden P. Ethnic population projections for the UK, 2001–2051. J Popul Res. 2012;29(1):45–89.
65. Bullivant S. The" No Religion" Population of Britain: Recent Data from the British Social Attitudes Survey (2015) and the European Social Survey. 2014 [cited 2021 April 19]. Available from; https://core.ac.uk/download/pdf/83952141.pdf
66. Abba K, Byrne P, Horton S, Lloyd-Williams M. Interventions to encourage discussion of end-of-life preferences between members of the general population and the people closest to them-a systematic literature review. BMC Palliat Care. 2013;12(1):1–2.
67. Hickey D, Quinn S. I don't want to talk about it. Raising public awareness of end-of-life care planning in your locality. Int J Palliat Nurs. 2012;18:241–7.
68. Mc Kenna D, O'Shea J, Tanner L. The Heart of Living and Dying: Upstreaming Advance Care Planning into Community Conversations in the Public Domain in Northern Ireland. J Soc Work End Life Palliat Care. 2020;16(4):346–63.
69. Zaman S, Whitelaw A, Richards N, Inbadas H, Clark D. A moment for compassion: emerging rhetorics in end-of-life care. Med Humanit. 2018;44(2):140–3.
70. Matjasko JL, Cawley JH, Baker-Goering MM, Yokum DV. Applying behavioral economics to public health policy: illustrative examples and promising directions. Am J Prev Med. 2016;50(5):S13–9.
71. Ledderer L, Kjær M, Madsen EK, Busch J, Fage-Butler A. Nudging in public health lifestyle interventions: a systematic literature review and metasynthesis. Health Educ Behav. 2020;47(5):749–64.
72. Presseau J, McCleary N, Lorencatto F, Patey AM, Grimshaw JM, Francis JJ. Action, actor, context, target, time (AACTT): a framework for specifying behaviour. Implement Sci. 2019;14(1):1–3.
73. Marie Curie. Creating a death literate society; The importance of boosting understanding and awareness of death, dying and bereavement in Northern Ireland. April 2022 [cited 2021, May 5]. Available from; https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/creating-a-death-literate-society.pdf.

Publisher's Note

Original Article

PALLIATIVE MEDICINE

Palliative Medicine
2021, Vol. 35(1) 120–129


Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/0269216320954339
journals.sagepub.com/home/pmj
SAGE

Validation of the Distress Thermometer in patients with advanced cancer receiving specialist palliative care in a hospice setting

Lisa Graham-Wisener[1], Martin Dempster[1], Aaroon Sadler[2], Luke McCann[3] and Noleen K McCorry[4]

Abstract

Background: Ongoing assessment of psychological reaction to illness in palliative and end of life care settings is recommended, yet validated tools are not routinely used in clinical practice. The Distress Thermometer is a short screening tool developed for use in oncology, to detect individuals who would benefit from further psychological assessment. However the optimal cut-off to detect indicative psychological morbidity in patients with advanced cancer receiving specialist palliative care is unclear.

Aim: To provide the first validation of the Distress Thermometer in an advanced cancer population receiving specialist palliative care in a UK hospice setting.

Design: Receiver Operating Characteristics analysis was used to compare the sensitivity and specificity of cut-offs indicative of psychological morbidity on the Distress Thermometer in comparison to the Hospital Anxiety and Depression Scale.

Setting/Participants: Data were derived from 202 patients with advanced cancer who were approached on admission to inpatient or day hospice care, with 139 patients providing complete data on both measures.

Results: The area under the curve was optimal using a Distress Thermometer cut-off score of ⩾6 for total distress and for anxiety, and a cut-off score of ⩾4 optimal when screening for depression.

Conclusions: The Distress Thermometer is a valid, accurate screening tool to be used in advanced cancer but with caution in relation to the lack of specificity. With little variation between the area under the curve scores, arguably a Distress Thermometer cut-off score of ⩾5 is most appropriate in screening for all types of psychological morbidity if sensitivity is to be prioritised.

Keywords

Palliative care, terminal care, anxiety, depression, validation studies, distress thermometer, advanced cancer, distress

What is already known about the topic?

- There is variation in the recommended Distress Thermometer cut-off scores for detecting indicative psychological morbidity, with need for revalidation when introducing the Distress Thermometer into new clinical populations, settings and cultures.
- There is a lack of consistency in the cut-off scores proposed by the limited number of Distress Thermometer validation studies within a palliative and end of life care setting, and no evidence of the optimal cut-off score for implementation of the Distress Thermometer with patients with advanced cancer in inpatient and day hospice settings

[1]Centre for Improving Health-Related Quality of Life, School of Psychology, Queen's University Belfast, Belfast, UK
[2]Marie Curie Hospice Belfast, Belfast, UK
[3]South Eastern Health and Social Care Trust, Ulster Hospital, Dundonald, Downpatrick, UK
[4]Centre of Excellence in Public Health, Queen's University Belfast, Belfast, UK

Corresponding author:
Lisa Graham-Wisener, Centre for Improving Health-Related Quality of Life, School of Psychology, Queen's University Belfast, David Keir Building, Belfast, BT7 1NN, UK.
Email: l.graham-wisener@qub.ac.uk

What this paper adds

- A cut-off score of ⩾6 is optimal when screening for total distress and for anxiety, and a Distress Thermometer cut-off score of ⩾4 is optimal when screening for depression in patients with advanced cancer receiving specialist palliative care in an inpatient/day hospice setting.
- With little variation between the area under the curve scores, arguably a Distress Thermometer cut-off score of ⩾5 is most appropriate in screening for all types of psychological morbidity if sensitivity is to be prioritised.
- Accuracy of the Distress Thermometer in screening for indicative psychological morbidity is fair to good in relation to sensitivity, but poor in relation to specificity with a number of false positives.

Implications for practice, theory or policy

- The Distress Thermometer is an accurate, valid screening tool for depression, anxiety and distress, and may be implemented in routine clinical practice to identify patients with advanced cancer receiving specialist palliative care in an inpatient/day hospice setting who would benefit from further psychological assessment.

Background

Psychological distress is defined as "a multi-factorial unpleasant emotional experience" which extends along a continuum, including a range of psychological morbidity from normal feelings of vulnerability to mood disorders including depression and anxiety disorder.[1] Heightened levels of psychological morbidity are reported in patients with advanced cancer receiving palliative and end of life care, with pooled prevalence of major depression at 14.3% and anxiety disorder at 9.8% according to Diagnostic and Statistical Manual of Mental Disorders or International Classification of Diseases definitions of psychological morbidity.[2] Untreated psychological morbidity is associated with increased physical symptom burden,[3,4] more challenging symptom management,[5] lack of acceptance of prognostic information,[6] a reduction in global health-related quality of life,[7] and may also be an independent prognostic indicator.[8] Importantly, when identified, there is evidence that psychological morbidity is amenable to change.[9] A systematic review recently established the effectiveness of brief psychosocial interventions (median of $n = 2$ sessions) on emotional distress among patients receiving palliative care.[10]

Evidence of complex need differentiates patients with advanced cancer who should be cared for by specialist palliative care services from those for whom non-specialist care is most appropriate.[11] Although there is a lack of certainty over how complexity is defined, complex emotional symptoms have been identified as a criteria by an international consensus[12] and healthcare professionals.[13] Clinical guidelines and quality indicators for specialist palliative care[14,15] recommend ongoing assessment of psychological reaction to illness with validated assessment tools. There is however indication that validated tools are not frequently used in specialist palliative care settings,[16,17] with psychological morbidity potentially under-reported and undertreated.[18]

Ultra-short screening tools (< 5 items) are attractive to clinicians because of their ease of use,[18] followed by a more lengthy assessment undertaken only for patients reporting clinically significant scores. The Distress Thermometer[19] is a single-item, 11-point visual analogue scale, with respondents indicating how distressed they have felt over the past week (from "No Distress" to "Extreme Distress"). In their guidelines the National Comprehensive Cancer Network suggest a cut-off score of ⩾5 in oncology samples as indicative of significant distress requiring additional assessment and treatment.[20] However, a meta-analysis of validation studies of the Distress Thermometer worldwide[21] proposed an alternative pooled score of ⩾4. A subsequent meta-analysis with subgroup analysis recommended an optimal cut-off ⩾6 for patients with cancer at the end of life,[22] however pointed out the inadequate specificity (< 0.60) of pooled scores at cut-offs of ⩾4 and ⩾5 from a limited number of available studies.[23], [24]

Despite recommendation for further validation work there has been little progress since publication of the meta-analyses,[22] with only four validation studies in total of the Distress Thermometer in palliative care settings.[25,26] The two studies published since the meta-analysis[22] propose an optimal clinical cut-off of ⩾5 and report high sensitivity but poor specificity (i.e. < 60%). There is acknowledged variation in Distress Thermometer clinical cut-offs according to instrument language, country, clinical population and setting, and therefore a need for revalidation in new populations.[21] A potential limitation of existing validation studies is that three[23,24,26] have derived data from either heterogeneous clinical populations of both patients with malignant and non-malignant disease[24,26] or across settings, for example, acute hospital and inpatient hospice units.[23] The other existing study[25] included a more homogenous sample of patients with advanced cancer with pain but in an acute hospital setting. Specialist palliative care settings may

include hospital, home, hospice inpatient units, outpatients and day services.[27] On the basis of the existing evidence, there is no clarity on which clinical cut-off is optimal for implementation of the Distress Thermometer with patients with advanced cancer in a hospice setting (inpatient or day hospice).

The current study provides the first validation of the Distress Thermometer in patients with advanced cancer receiving specialist palliative care in a hospice setting (inpatient & day hospice). The study aims to:

- Evaluate the sensitivity and specificity of the Distress Thermometer in screening for distress, anxiety and depression, using the Hospital Anxiety and Depression Scale[28] as a reference measure
- Identify the optimal cut-off points for the Distress Thermometer at which to make referrals for further psychological assessment
- Identify socio-demographic and clinical factors which are associated with heightened psychological morbidity among this population

Method

Description of the data and the population

A secondary analysis of data held by a UK hospice was undertaken. The hospice services include an 18-bed inpatient unit, and a day hospice with 5 clinics per week. The data were previously collected during the course of routine care to inform a psychological needs assessment. The psychological needs assessment database contained data on patients consecutively admitted to day hospice or the inpatient unit between September 2014 and August 2016. The Distress Thermometer[19] and the Hospital Anxiety and Depression Scale[28] were administered upon patient admission, and completed independently by the patient, or with clinician support if needed. Both measures were administered consecutively (Hospital Anxiety and Depression Scale followed by Distress Thermometer) by palliative care physicians who were unaware of the patient's score on the reference test (Hospital Anxiety and Depression Scale) which was calculated at later date. For the patients who were approached for screening, demographic and clinical data were collected alongside reasons for non-completion where appropriate. For the purposes of the current study, data of all patients were eligible for inclusion in the secondary analysis, with the exception of data from patients with non-malignant disease.

Measures

Socio-demographic and clinical characteristics. Data included disease malignancy, International Classification of Diseases-10 disease classification- neoplasms,[29] locally advanced/metastatic disease, Eastern Cooperative Oncology Group performance status,[30] previous mental health condition (yes/no) and if currently prescribed specific medication (opiates, anxiolytics, anti-depressants, hypnotics, anti-psychotics, anti-epileptics). Socio-demographic data included age, gender, ethnicity, and marital status.

Screening Measures. The Distress Thermometer Version 2[19] is the index test. The Distress Thermometer is a single-item, 11-point visual analogue scale, with respondents indicating how distressed they have felt over the past week (from "No Distress" to "Extreme Distress").

The Hospital Anxiety and Depression Scale[28] is the reference measure. The Hospital Anxiety and Depression Scale is a 14-item questionnaire for physically ill patients with two subscales; anxiety (Hospital Anxiety and Depression Scale-Anxiety;7-items) and depression (Hospital Anxiety and Depression Scale-Depression;7-items) with each item rated on a 0 to 3 scale. Each subscale has a total score ranging from 0 to 21, with a higher total score indicating a higher level of anxiety or depression. A total overall score for distress [Hospital Anxiety and Depression Scale-Total] ranges from 0 to 42. Guidelines suggest clinical caseness of $\geqslant$8 on each subscale, and $\geqslant$15 for total score.[31] The Hospital Anxiety and Depression Scale is the most frequently used mood scale in cancer and palliative settings,[32] and the most frequently used reference measure for validation of the Distress Thermometer in cancer populations.[21]

Analysis

Statistical analysis was performed using the Statistical Package for Social Sciences (version 22.0). Demographic and clinical data were analyzed using descriptive statistics. The relationship between demographic/clinical characteristics and distress was investigated with correlations, independent *t*-tests, and analysis of variance. Receiver operating characteristics analysis was used to compare the three recommended cut-off points of the Distress Thermometer (4, 5 & 6)[20–22] to the Hospital Anxiety and Depression Scale cut-off scores of $\geqslant$8 on each subscale, and $\geqslant$15 for total score.[32] The optimal cut-off score was determined according to the point at the top left of the curve. The sensitivity, specificity, positive predictive value, negative predictive value and positive and negative likelihood ratios were calculated for each cut-off of the Distress Thermometer score against the Hospital Anxiety and Depression Scale.

Sample size calculation

A medium effect size is equivalent to an area under the curve in receiver operating characteristics analysis of

0.639.[33] A sample size of 138 is sufficient to detect an area under the curve of 0.639 with 90% power, using an alpha value of 0.05.

Ethics

National Health Service research ethics approval for the secondary analysis was obtained from Office for Research Ethics Committees Northern Ireland (REC reference: 17/NI/0036) and research governance approval from the Marie Curie Hospice Belfast Research Governance Committee.

Results

All patients were offered the measures to complete upon admission, with the exception of those patients who were unconscious at the time of admission, had rapidly deteriorating health, fatigue, agitation or confusion (n = 141 inpatient unit). A total of 202 patients were approached for screening. Five patients declined to participate and another 29 were not able to participate primarily because they were too unwell. Of the remaining 168 patients, 139 provided complete information on the Hospital Anxiety and Depression Scale and Distress Thermometer. Participants had a mean (standard deviation) age of 67.26 (11.72) years. Table 1 shows the other medical and demographic information for this sample.

Table 1. Characteristics of hospice patients (n = 139).

	N (%)
Gender	
Male	53 (38)
Female	86 (62)
Ethnicity	
White	136 (98)
Other	3 (2)
Marital Status	
Never Married	16 (12)
Divorced	18 (13)
Married/Long Term Partner	74 (53)
Widowed	31 (22)
Locally Advanced/Metastatic	
Locally Advanced	44 (32)
Metastatic	92 (67)
Haematological	1 (0.7)
Missing data	2 (1.4)
Eastern Cooperative Oncology Group performance status	
1	50 (37)
2	31 (23)
3	43 (32)
4	12 (9)
Missing data	3 (2.2)
Previous mental health issues (yes/no)	59/139 (42)
Current Medication	
Opiates	108 (78)
Anxiolytics	33 (24)
Anti Depressants	43 (31)
Hypnotics	20 (14)
Anti Psychotics	14 (10)
Anti Epileptics	30 (22)
Cancer Site	
Respiratory & intrathoracic	40 (29)
Digestive organs	31 (22)
Breast	19 (14)
Urinary tract	12 (9)
Female genital organs	7 (5)
Male genital organs	6 (4)
Lip, oral cavity & pharynx	6 (4)
Other	18 (13)

Distress thermometer and hospital anxiety and depression scale descriptive statistics

Scores on the Distress Thermometer ranged from 0 to 10, with a mean score of 5.40 (standard deviation = 2.91). The total Hospital Anxiety and Depression Scale score ranged from 2 to 34, with a mean score of 17.35 (standard deviation = 8.31). Mean (standard deviation) scores for the anxiety and depression subscales of the Hospital Anxiety and Depression Scale were 8.55 (4.76) and 8.80 (4.69) respectively. The number of participants experiencing clinically significant levels of anxiety, depression and overall distress according to the Hospital Anxiety and Depression Scale were 79/139 (43%), 86/139 (62%) and 87/139 (63%), respectively.

Receiver operating characteristic analysis and optimal cut-off score

The scores from the Distress Thermometer were compared to Hospital Anxiety and Depression Scale total, anxiety, and depression scores, using receiver operating characteristics analysis (see Table 2).

Table 2 indicates between 66% and 74% of cases of clinically significant psychological morbidity would be correctly identified for referral for further assessment. Using recommended guidelines,[34] the overall performance reports poor to fair discrimination across all cut-offs (see Figures 1–3).

The area under the curve was optimal with a Distress Thermometer cut-off $\geqslant$6 for distress, with a Distress Thermometer cut-off $\geqslant$6 for anxiety and a Distress Thermometer cut-off $\geqslant$4 for depression. However, there is little difference between the area under the curve scores for the different Distress Thermometer cut-off points. Table 3 reports cross tabulation of the index test results (Distress Thermometer) by the results of the reference standard (Hospital Anxiety and Depression Scale-Depression, Hospital Anxiety and Depression Scale-Anxiety & Hospital Anxiety and Depression Scale-Total Score).

Table 2. Results of a receiver operating characteristics analysis for distress thermometer cut-off scores of 4 to 6 compared with the hospital anxiety and depression scale.

	Proposed cut-off on distress thermometer	Area under the curve (95% CI)	Sensitivity	Specificity	Positive predictive value	Negative predictive value	Positive likelihood ratio	Negative likelihood ratio
Hospital Anxiety and Depression Scale-Total ⩾15	4	0.696 (0.601–0.792)	0.874	0.519	0.752	0.711	1.82	0.24
Hospital Anxiety and Depression Scale-Total ⩾15	5	0.698 (0.605–0.792)	0.782	0.615	0.773	0.627	2.03	0.35
Hospital Anxiety and Depression Scale-Total ⩾15	6	0.699 (0.608–0.789)	0.667	0.731	0.806	0.567	2.48	0.46
Hospital Anxiety and Depression Scale-Anxiety ⩾8	4	0.729 (0.640–0.818)	0.924	0.533	0.598	0.894	1.98	0.14
Hospital Anxiety and Depression Scale- Anxiety ⩾8	5	0.720 (0.631–0.808)	0.823	0.617	0.620	0.817	2.15	0.29
Hospital Anxiety and Depression Scale- Anxiety ⩾8	6	0.736 (0.650–0.821)	0.722	0.750	0.683	0.776	2.89	0.37
Hospital Anxiety and Depression Scale- Depression ⩾8	4	0.676 (0.579–0.772)	0.860	0.491	0.733	0.684	1.69	0.29
Hospital Anxiety and Depression Scale- Depression ⩾8	5	0.661 (0.566–0.756)	0.756	0.566	0.739	0.588	1.74	0.43
Hospital Anxiety and Depression Scale- Depression ⩾8	6	0.675 (0.582–0.767)	0.651	0.698	0.778	0.552	2.16	0.50

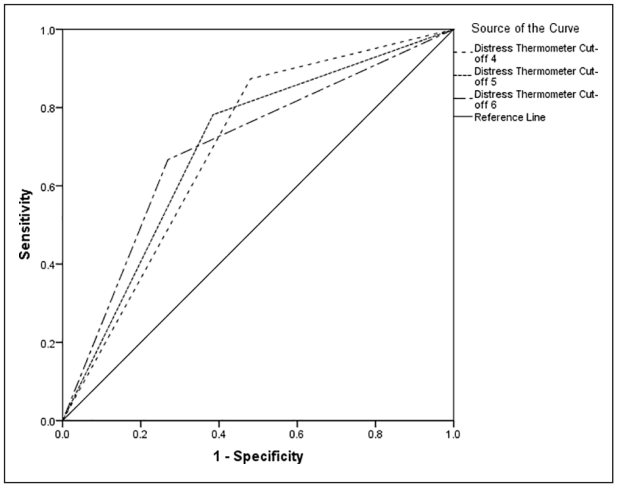


Figure 1. Receiver operating characteristics curve for Hospital Anxiety and Depression Scale-Total Score.

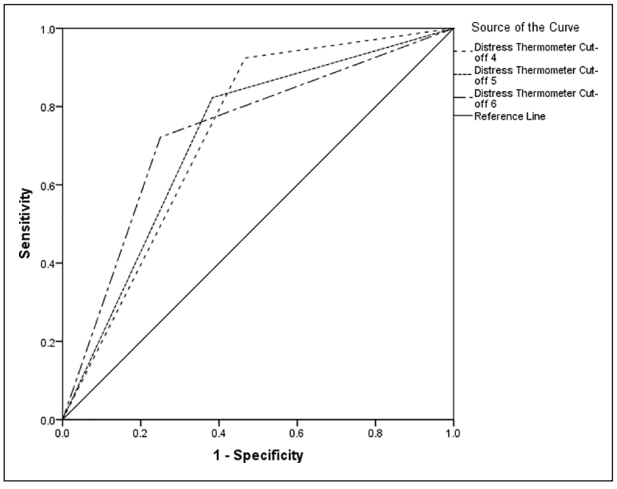


Figure 2. Receiver operating characteristics curve for Hospital Anxiety and Depression Scale-Anxiety Score.

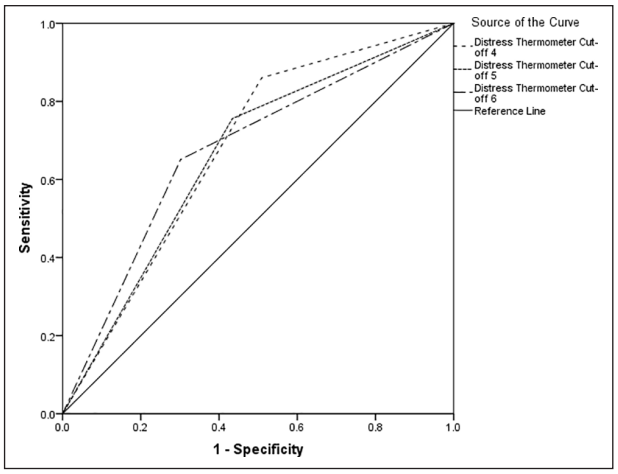


Figure 3. Receiver operating characteristics curve for Hospital Anxiety and Depression Scale-Depression Score.

Table 3. Frequency of correct and incorrect classifications when using the Distress Thermometer cutoff ⩾5, with the Hospital Anxiety and Depression Scale cutoffs as reference standard.

	Index test (Distress Thermometer) cut-off score	
Reference test (Hospital Anxiety and Depression Scale) cutoff score	Below distress thermometer cut-off ⩾5 *N* (%)	Above distress thermometer cut-off ⩾5 *N* (%)
Below Hospital Anxiety and Depression Scale-Depression⩾8 *N* (%)	30 (22%)	23 (17%)
Above Hospital Anxiety and Depression Scale-Depression ⩾8 *N* (%)	21 (15%)	65 (47%)
Below Hospital Anxiety and Depression Scale-Anxiety⩾8 *N* (%)	37 (27%)	23 (17%)
Above Hospital Anxiety and Depression Scale-Anxiety⩾8 *N* (%)	14 (10%)	65 (47%)
Below Hospital Anxiety and Depression Scale-Total⩾15 *N* (%)	32 (23%)	20 (14%)
Above Hospital Anxiety and Depression Scale-Total⩾15 *N* (%)	19 (14%)	68 (49%)

Factors influencing the distress thermometer and hospital anxiety and depression scale

There was a weak, negative correlation found between age and the Hospital Anxiety and Depression Scale-Anxiety ($r = -0.19$, $p = 0.027$), the Hospital Anxiety and Depression (−0.19, $p = 0.026$), and the Distress Thermometer ($r = -0.27$, $p = 0.001$). Associations with the other demographic and clinical variables are reported in Table 4. There was a moderate-large effect on Hospital Anxiety and Depression Scale-Anxiety, Hospital Anxiety and Depression Scale–Depression, Hospital Anxiety and Depression Scale-Total and the Distress Thermometer among respondents with previous mental health issues and those who have been prescribed anxiolytics or anti-depressants. Females scored moderately higher on the Hospital Anxiety and Depression Scale-Anxiety and the Hospital Anxiety and Depression Scale-Total and those prescribed hypnotics scored moderately higher on the Distress Thermometer. Those who were divorced scored moderately higher on the Hospital Anxiety and Depression Scale-Depression and Hospital Anxiety and Depression Scale-Total; and those prescribed opiates or with a performance status score of 4 scored moderately higher on the Hospital Anxiety and Depression Scale-Depression.

Discussion

This study provides the first validation of the Distress Thermometer in an advanced cancer population receiving specialist palliative care in a day or inpatient hospice setting. This adds to the small number of studies[23–26] suggesting the Distress Thermometer to be a valid method for screening for indicative psychological morbidity in palliative care.

The optimal Distress Thermometer cutoff according to the area under the curve when screening for distress and anxiety is proposed as ⩾6 for distress and anxiety and as ⩾4 for depression in the current study. It must however be noted that there is little difference between the area under the curve score for Distress Thermometer cut-offs ⩾4, ⩾5 and ⩾6, yet Distress Thermometer cut-offs, ⩾5 and ⩾6 offer the smallest range of confidence interval. It is therefore the decision of the authors to amend the test decision criterion to alter the balance between sensitivity and specificity towards developing an optimal screening test. In their systematic review,[22] Ma and colleagues argue for a Distress Thermometer cut-off ⩾6 to increase the specificity of the measure with a trade-off in relation to sensitivity. We recommend the utility of the Distress Thermometer as a distress screening measure be prioritized, which places emphasis on the ability of the tool to identify those without the disorder with minimal false negatives. On this basis we believe a Distress Thermometer cut-off of ⩾5 to be optimal in screening for distress (Sensitivity-0.78, Specificity-0.62), for anxiety (Sensivity-0.82, Specificity-0.62) and for depression (Sensitivity = 0.76, Specificity-0.57). This ensures that sensitivity is prioritized above specificity (reported as fair to good), while guaranteeing specificity to be at a level higher than chance (reported as poor to fair). With a

Table 4. One-way ANOVA of associations between demographic and clinical variables and distress thermometer/hospital anxiety and depression scale scores.

	Distress thermometer	Hospital anxiety and depression scale- anxiety	Hospital anxiety and depression scale- depression	Hospital anxiety and depression scale-total
Gender	$F(1,137) = 3.15$, $p = 0.078$	$F(1,137) = 13.04$, $p < 0.001$*	$F(1,137) = 1.84$, $p = 0.177$	$F(1,137) = 7.93$, $p = 0.006$*
Marital status	$F(3,135) = 1.77$, $p = 0.156$	$F(3,135) = 1.78$, $p = 0.155$	$F(3,135) = 3.02$, $p = 0.032$*	$F(3,135) = 3.06$, $p = 0.030$*
Locally advanced vs metastatic	$F(1,137) = 1.74$, $p = 0.189$	$F(1,137) = 1.21$, $p = 0.274$	$F(1,137) = 2.59$, $p = 0.109$	$F(1,137) = 2.38$, $p = 0.125$
Performance status	$F(3,132) = 1.51$, $p = 0.216$	$F(3,132) = 0.66$, $p = 0.580$	$F(3,132) = 4.29$, $p = 0.006$*	$F(3,132) = 2.48$, $p = 0.064$
Previous mental health issues	$F(1,137) = 21.70$, $p < 0.001$*	$F(1,137) = 33.47$, $p < 0.001$*	$F(1,137) = 16.02$, $p < 0.001$*	$F(1,137) = 32.25$, $p < 0.001$*
Cancer site	$F(7,131) = 1.12$, $p = 0.353$	$F(7,131) = 2.07$, $p = 0.051$	$F(7,131) = 0.71$, $p = 0.664$	$F(7,131) = 0.53$, $p = 0.811$
Medication-				
Opiates	$F(1,137) = 0.08$, $p = 0.780$	$F(1,137) = 0.12$, $p = 0.728$	$F(1,137) = 6.31$, $p = 0.013$*	$F(1,137) = 2.57$, $p = 0.112$
Anxiolytics	$F(1,137) = 9.50$, $p = 0.002$*	$F(1,137) = 16.02$, $p < 0.001$*	$F(1,137) = 19.53$, $p < 0.001$*	$F(1,137) = 23.81$, $p < 0.001$*
Anti-Depressants	$F(1,137) = 6.33$, $p = 0.013$*	$F(1,137) = 11.62$, $p = 0.001$*	$F(1,137) = 5.06$, $p = 0.026$*	$F(1,137) = 10.49$, $p = 0.002$*
Hypnotics	$F(1,137) = 4.76$, $p = 0.031$*	$F(1,137) = 3.58$, $p = 0.061$	$F(1,137) = 2.42$, $p = 0.122$	$F(1,137) = 3.87$, $p = 0.051$
Anti-psychotics	$F(1,137) = 0.51$, $p = 0.478$	$F(1,137) = 0.08$, $p = 0.779$	$F(1,137) = 0.17$, $p = 0.684$	$F(1,137) = 0.01$, $p = 0.944$
Anti-Epileptics	$F(1,137) = 1.27$, $p = 0.262$	$F(1,137) = 0.63$, $p = 0.428$	$F(1,137) = 0.56$, $p = 0.456$	$F(1,137) = 0.77$, $p = 0.381$

cut-off of $\geqslant 5$ the Distress Thermometer reports poor case-finding ability however the cost of false positives is likely to be material; time/cost on further psychological assessment. A Distress Thermometer cut-off of $\geqslant 5$ is in line with the existing research in palliative care.[23-26] Across all cut-offs the specificity is poor to fair, which may be as the Distress Thermometer was developed as a screen for multi-factorial distress rather than simply clinical mood disorders. It may be that rather than the Distress Thermometer detecting anxiety or depression, it is detecting variance shared with general distress. It is important to consider the performance of the measure within this broader context.

There has been limited validation of unidimensional measures for complex psychological constructs,[18] despite evidence that clinicians prefer slightly less accurate but briefer screening measures[35] suggesting that the Distress Thermometer may be acceptable in practice. The accuracy reported of the Distress Thermometer in the current study is in line with other ultra-short distress screening measures,[18] the existing Distress Thermometer validation studies in palliative care[23–26] and the broader Distress Thermometer validation research in oncology.[21] Using any Distress Thermometer cut-off, the sensitivity of the Distress Thermometer is poor to good, however the specificity is poor to fair. The Distress Thermometer is good at identifying psychological morbidity, but poor at identifying individuals without psychological morbidity with a high degree of false positives. This contributes towards an area under the curve which is poor to fair. It must be considered however that in mental health research where the index test is unlikely to be perfect, it is impossible for the area under the curve to reach 1.00.[36] When questionnaires produce an area under the curve greater than 0.90, it is more likely to indicate design flaws.[37]

Strengths and limitations

The current study has a number of strengths. The sample size ($n = 139$) is relatively large for a population receiving specialist palliative care. This is the first validation study specifically with a hospice population (inpatient and day hospice) and therefore provides accurate clinical cut-offs for use of the Distress Thermometer as a psychological screening tool in this setting. Importantly, the current study derived data only from patients with advanced cancer, as with only two other studies internationally.[23,25] This is an improvement from a significant number of validation studies deriving data from patients at various stages of the cancer trajectory.[21]

There are several limitations to the current study. Firstly, the Hospital Anxiety and Depression Scale[28] was used as the reference test rather than the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders –V.[5,38] However, with one exception[23] the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders is rarely used as the reference measure for validation of the Distress Thermometer. The Hospital Anxiety and Depression Scale is the dominant reference test in validation studies of the Distress Thermometer.[21] It must however be acknowledged that there is uncertainty with the latent structure of the measure[39] in addition to the content validity.[40] Authors have proposed the Hospital Anxiety and Depression Scale best fits a bifactor structure and suffers from saturation of a general distress factor, meaning there are issues distinguishing between anxiety and depression.[39] This therefore results in more confidence in the use of the Hospital Anxiety and Depression Scale as a reference test for distress rather than for anxiety or depression. Lastly, with acknowledgement that the Distress Thermometer needs to be revalidated in different cultures[21] the generalizability of these findings outside of the UK/Ireland warrants caution. However, our proposed Distress Thermometer cut-off $\geqslant$5 aligns to recommendations based upon Chinese[25] and German[26] palliative care samples with similar performance in relation to sensitivity and specificity which may suggest that clinical characteristics and setting are more important determinants.

Implications for practice

There is evidence that the majority of palliative care providers do not use a validated tool to screen for psychological morbidity.[16,17] Clinical guidelines for distress management in cancer populations recommend screening for distress in all patients, followed by clinical diagnostic interview for those who screen positive.[41–43] Palliative care guidelines[44] are consistent with this recommendation but do not identify specific examples of tools to be used, or the timing of administration, instead emphasizing, "whenever possible and appropriate, a validated and context-specific assessment tool is used;"[44] p64]. The current study administered the Distress Thermometer and Hospital Anxiety and Depression Scale on admission to hospice, identifying a significant proportion of patients experiencing clinically significant levels of anxiety, depression and overall distress. This provides evidence of the utility of screening at this early stage within the hospice setting. The findings suggest that particular attention should be given to patients, who are younger, female, have previous mental health issues and who have been prescribed anxiolytics, antidepressants, opiates and hypnotics. It is also worth noting the recommendation that tools with acceptable sensitivity among patients with high symptom burden are particularly needed.[17] The Distress Thermometer as a one-item measure is quick to administer and unlike other tools used within this setting[45] does not rely on aspects of psychological morbidity that are also common somatic symptoms of illness.

Future research

There is some evidence that the accuracy of the Distress Thermometer can be improved with the addition of three emotion thermometers (depression, anxiety, anger) and one outcome thermometer (need for help).[46,47] As far as the authors are aware the addition of emotion thermometers has not been validated in a palliative care setting, and hence this is an important area for future research. There is evidence in cancer settings demonstrating patient acceptability of a five-step process integrating the Distress Thermometer with patient review, need for help and referral information.[48] Further research is needed to ensure use of the Distress Thermometer is integrated within an evidence-based pathway for identification and management of distress.[16,17]

Conclusion

In conclusion, findings suggest that the Distress Thermometer is a valid, ultra-short screening measure for use with advanced cancer patients receiving specialist palliative care in the inpatient or day hospice setting. It is recommended that specialist palliative care clinicians implementing the Distress Thermometer in this setting should use a cut-off of $\geqslant$5 when screening for anxiety, depression or distress. As the specificity of the measure is poor, service providers should be aware of potential for significant false positives and ensure the Distress Thermometer is integrated within an evidence-based pathway which includes further psychological assessment.

Acknowledgements

The authors would like to thank Pauline Wilkinson for her contribution to this research, in addition to the clinical team at Marie Curie Hospice Belfast for their efforts in collecting the original data.

Authorship

LGW, MD, NMcC contributed to the design of the work, with LGW, MD, AS, LMcC and NMcC contributing to the acquisition, analysis and interpretation of data. LGW drafted the article with critical revision by MD, NMcC,, AS and LMcC. All authors have approved the version to be published and have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: A Sadler's hospice post is supported by Marie Curie.

ORCID iDs

Lisa Graham-Wisener https://orcid.org/0000-0001-6311-4978
Martin Dempster https://orcid.org/0000-0001-9499-3186
Noleen K McCorry https://orcid.org/0000-0002-8542-7665

References

1. National Comprehensive Cancer Network. *NCCN clinical practice guidelines in oncology: distress management*. Fort Washington, PA: NCCN; 2010. Version 1.2011, http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf (free registration required) (2011, accessed 18 June 2020).
2. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011; 12(2): 160–174.
3. Grotmol KS, Lie HC, Loge JH, et al. Patients with advanced cancer and depression report a significantly higher symptom burden than non-depressed patients. *Palliat Support Care* 2018; 1–7.
4. Mercadante S, Adile C, Ferrera P, et al. Symptom hyperexpression in advanced cancer patients with anxiety and depression admitted to an acute supportive/palliative care unit. *Support Care Cancer* 2019; 1–8.
5. Rayner L, Lee W, Price A, et al. The clinical epidemiology of depression in palliative care and the predictive value of somatic symptoms: cross-sectional survey with four-week follow-up. *Palliat Med* 2011; 25(3): 229–241.
6. Derry HM, Maciejewski PK, Epstein AS, et al. Associations between anxiety, poor prognosis, and accurate understanding of scan results among advanced cancer patients. *J Palliat Med* 2019; 22(8): 961–965.
7. Grotmol KS, Lie HC, Hjermstad MJ, et al. European Palliative Care Research Collaborative (EPCRC. Depression—a major contributor to poor quality of life in patients with advanced cancer. *J Pain Symptom Manag* 2017; 54(6): 889–897.
8. Lloyd-Williams M, Shiels C, Taylor F, et al. Depression—an independent predictor of early death in patients with advanced cancer. *J Affect Disord* 2009; 113(1–2): 127–132.
9. Uitterhoeve RJ, Vernooy M, Litjens M, et al. Psychosocial interventions for patients with advanced cancer–a systematic review of the literature. *Br J Cancer* 2004; 91(6): 1050.
10. Warth M, Kessler J, Koehler F, et al. Brief psychosocial interventions improve quality of life of patients receiving palliative care: a systematic review and meta-analysis. *Palliat Med* 2019; 33: 332–345.
11. Commissioning Guidance for Specialist Palliative Care. *Helping to deliver commissioning objectives*. London: Guidance document published collaboratively with Association for Palliative Medicine of Great Britain and Ireland; Consultant Nurse in Palliative Care Reference Group; Marie Curie Cancer Care; National Council for Palliative Care and Palliative Care Section of the Royal Society of Medicine; 2012.
12. Hui D, Mori M, Watanabe SM, et al. Referral criteria for outpatient specialty palliative cancer care: an international consensus. *Lancet Oncol* 2016; 17(12): e552–e559.
13. Carduff E, Johnston S, Winstanley C, et al. What does 'complex'mean in palliative care? Triangulating qualitative findings from 3 settings. *BMC Palliat Care* 2018; 17(1): 12.
14. National Coalition for Hospice and Palliative Care. Clinical practice guidelines for quality palliative care, 4th ed. 2018. https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf (accessed 4 April 2019).
15. McCorry N, O'Connor S, Leemans K, et al. Quality indicators for Palliative Day Services: a modified Delphi study. *Palliat Med* 2019; 33(2): 197–205
16. Atkin N, Vickerstaff V and Candy B. 'Worried to death': the assessment and management of anxiety in patients with advanced life-limiting disease, a national survey of palliative medicine physicians. *BMC Palliat Care* 2017; 16(1): 69.
17. Kozlov E, Eghan C, Moran S, et al. Palliative care providers' practices surrounding psychological distress screening and treatment: a national survey. *Am J Hospice Palliat Med* 2018; 35(7): 938–944.
18. Thekkumpurath P, Venkateswaran C, Kumar M, et al. Screening for psychological distress in palliative care: a systematic review. *J Pain Symp Manage* 2008; 36(5): 520–528.
19. Roth AJ, Kornblith AB, Batel-Copel L, et al. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998; 82(10): 1904–1908.
20. Holland JC, Andersen B, Breitbart WS, et al. Distress management. *J Natl Compr Canc Netw* 2010; 8(4): 448–485.
21. Donovan KA, Grassi L, McGinty HL, et al. Validation of the distress thermometer worldwide: state of the science. *Psycho-oncol* 2014; 23(3): 241–250.
22. Ma X, Zhang J, Zhong W, et al. The diagnostic role of a short screening tool—the distress thermometer: a meta-analysis. *Support Care Cancer* 2014; 22(7): 1741–1755.
23. Ryan DA, Gallagher P, Wright S, et al. Sensitivity and specificity of the Distress Thermometer and a two-item depression screen (Patient Health Questionnaire-2) with a 'help'question for psychological distress and psychiatric morbidity in patients with advanced cancer. *Psycho-Oncol* 2012; 21(12): 1275–1284.
24. Thekkumpurath P, Venkateswaran C, Kumar M, et al. Screening for psychological distress in palliative care: performance of touch screen questionnaires compared with semistructured psychiatric interview. *J Pain Symp Manage* 2009; 38(4): 597–605.
25. Guan B, Wang K, Shao Y, et al. The use of distress thermometer in advanced cancer inpatients with pain. *Psycho-Oncol* 2019; 28(5): 1004–1010.
26. Wüller J, Küttner S, Foldenauer AC, et al. Accuracy of the distress thermometer for home care patients with palliative care needs in Germany. *Palliat Support Care* 2017; 15(3): 288–294.
27. Cox S, Murtagh FEM and Tookman A. A review of specialist palliative care provision and access across London – mapping the capital. *London J Prim Care* 2017; 9(3): 33–37.
28. Zigmond AS and Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983; 67(6): 361–370.
29. World Health Organisation. *International statistical classification of diseases and related health problems 10th*

revision (ICD-10)-WHO version. https://icd.who.int/browse10/2016/en (2016, accessed 5 July 2019).
30. Zubrod CG, Schneiderman M, Frei E, et al. Appraisal of methods for the study of chemotherapy of cancer in man: comparative therapeutic trial of nitrogen mustard and triethylene thiophosphoramide. *J Chron Dis* 1960; 11(11): 7–33.
31. Herrmann C. International experiences with the Hospital Anxiety and Depression Scale-a review of validation data and clinical results. *J Psychosom Res* 1997; 42(1): 17–41.
32. Mitchell AJ, Meader N and Symonds P. Diagnostic validity of the hospital anxiety and depression scale (HADS) in cancer and palliative settings: a meta-analysis. *J Affect Disord* 2010; 126: 335–348.
33. Rice ME and Harris GT. Comparing effect sizes in follow-up studies: ROC area, Cohen's d and r. *Law Hum Behav* 2005; 29(5): 615-620.
34. Swets JA, Dawes RM and Monahan J. Better decisions through science. *Sci Am* 2000; 283(4): 82–87.
35. Mitchell AJ, Kaar S, Coggan C, et al. Acceptability of common screening methods used to detect distress and related mood disorders—preferences of cancer specialists and non-specialists. *Psycho-Oncol* 2008; 17(3): 226–236.
36. Pepe MS. *The statistical evaluation of medical tests for classification and prediction*. New York: NY: Wiley; 2003
37. Youngstrom EA, Meyers OI, Youngstrom JK, et al. Comparing the effects of sampling designs on the diagnostic accuracy of eight promising screening algorithms for pediatric bipolar disorder. *Biol Psychiatry* 2006; 60: 1013–1019.
38. American Psychiatric Association. *Structured clinical interview for DSM-5 (SCID-5)*, 2015. http://www.appi.org/products/structured-clinical-interview-for-dsm5-scid-5
39. Norton S, Cosco T, Doyle F, et al. The Hospital Anxiety and Depression Scale: a meta confirmatory factor analysis. *J Psychosom Res* 2013; 74(1): 74–81.
40. Coyne JC and van Sonderen E. No further research needed: abandoning the Hospital and Anxiety Depression Scale (HADS). *J Psychosom Res* 2012; 72(3): 173.
41. Andersen BL, DeRubeis RJ, Berman BS, et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. *J Clin Oncol* 2014; 32: 1605–1619.
42. Butow P, Price MA, Shaw JM, et al. Clinical pathway for the screening, assessment and management of anxiety and depression in adult cancer patients: Australian guidelines. *Psychooncol* 2015; 24: 987–1001.
43. Howell D, Keshavarz H, Esplen MJ, et al. A pan Canadian practice guideline: screening, assessment and care of psychosocial distress (depression, anxiety) in adults with cancer. Canadian partnership against cancer (cancer journey advisory group) and Canadian association of psychosocial. *Oncology* 2015; http://www.capo.ca/wp-content/uploads/2010/10/Distress_guideline_CAPO_201507311.pdf (accessed 26 November 2016).
44. Clinical Practice Guidelines for Quality Palliative Care. *National consensus project for quality palliative care*. 2013. http://www.nationalcoalitionhpc.org/ncp-guidelines-2013/ (2017, accessed 5 July 2019).
45. Bruera E, Kuehn N, Miller MJ, et al. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991; 7(2): 6–9.
46. Mitchell AJ, Baker-Glenn EA, Granger L, et al. Can the distress thermometer be improved by additional mood domains? Part I. Initial validation of the emotion thermometers tool. *Psycho-Oncology* 2010; 19(2): 125–133.
47. Mitchell AJ, Baker-Glenn EA, Park B, et al. Can the distress thermometer be improved by additional mood domains? Part II. What is the optimal combination of Emotion Thermometers? *Psycho-Oncology* 2010; 19(2): 134–140.
48. van Nuenen FM, Donofrio SM, van de Wiel HB, et al. Cancer patients' experiences with and opinions on the process' Screening of Distress and Referral Need'(SDRN) in clinical practice: a quantitative observational clinical study. *PLoS One* 2018; 13(6): e0198722.

QUEEN'S UNIVERSITY BELFAST

COMPASSIONATE COMMUNITIES POSITION PAPER

Fostering Compassionate Communities: A Call to Transform Caregiving, Dying, Death and Grieving on the Island of Ireland

Authors: Lisa Graham-Wisener, Stephanie Crawford & Ashleen Crowe

AIIHPC
The All Ireland Institute of Hospice and Palliative Care

Irish Hospice Foundation

Foyle Hospice
Together we care

HSC Public Health Agency

An Roinn Gnóthaí Eachtracha
Department of Foreign Affairs

CONTENTS

EXECUTIVE SUMMARY

Across the island of Ireland, the role of caring for people through serious illness, dying, death and grief was once widely recognised as being centred in the community. However, as palliative and end-of-life care services have advanced to make significant improvements in quality of life for individuals with serious illness and their families, society has come to view responsibility for death and dying as primarily that of healthcare professionals. This shift has led to communities feeling less confident, knowledgeable, and prepared to provide compassionate support around end-of-life.

This comes at a time when the death rate is expected to more than double across the island of Ireland in the next twenty years, coupled with an increase in the number of people dying at home [1, 2]. Many people with serious illness and their families already lack the support they need, and this gap is likely to widen in future. To achieve the highest quality and continuity of care, we argue that entire communities should be empowered to take the lead in caring for people around the end-of-life, supported by our specialist and generalist palliative care services and wider civic society. To this end, we believe that a compassionate communities approach is urgently needed to transform how we experience life and death on the island of Ireland.

This position paper proposes recommendations for supporting the development of a compassionate communities approach to caregiving, dying, death and grieving on the island of Ireland. It has been developed by Dr Lisa Graham-Wisener, Dr Ashleen Crowe and Stephanie Crawford from the School of Psychology at Queen's University Belfast. Findings in the position paper were informed by the *Inaugural Compassionate Communities in Palliative and End of Life Care Conference, Newry*, 9th September 2024 (see methods section below). This work was funded through the Shared Island Civic Society Fund from the Department of Foreign Affairs Ireland and Northern Ireland Public Health Agency, with partnership working from the All Ireland Institute for Hospice and Palliative Care, Foyle Hospice, and the Irish Hospice Foundation.

The position paper begins by outlining what the compassionate communities movement is, with a discussion of why a compassionate communities approach is needed on the island of Ireland and how this supports national policies in health and social care. This is followed by an overview of progress to date in developing community responses to caregiving, dying, death and grieving on the island of Ireland, followed by key recommendations.

The report details that:

Compassionate communities empower people to support one another through serious illness, dying, death, and grief, recognising these as shared human experiences rather than solely the responsibility of health and social care. Compassionate communities complement, rather than replace, formal services by fostering local networks of care and compassion. The compassionate communities movement also recognises that **death is everyone's business** and advocates for **wider systemic change** to ensure that individuals facing the challenges associated with serious illness encounter compassion in all aspects of their lives, including in schools, workplaces, and trade unions.

A compassionate communities approach is **highly relevant to the changing demographic profile** of our population on the island of Ireland and may contribute to addressing the particular challenges we currently experience around end-of-life, including **reducing the burden on our overstretched health and social care services**. This approach complements efforts to promote **integrated care**—a key principle in delivering seamless, person-centred support that spans community and professional services. Fostering compassionate communities across the island of Ireland **aligns to North/South national policies**, such as the new National Adult Palliative Care Policy (2024) in Ireland and both evolving Programmes for Government which place an emphasis on integrated care and community-based support. Fostering compassionate communities also presents significant **opportunities for cross-border cooperation.**

The compassionate communities model is **underdeveloped** across the island of Ireland, although there is **considerable cross-sector interest** in its advancement. The key challenges and opportunities for fostering compassionate communities are outlined below.

Table 1: Summarised key findings of conference including challenges and opportunities

KEY FINDINGS	CHALLENGES	OPPORTUNITIES
Compassionate communities initiatives need to be recognised as creating the environment for meaningful education, social awareness raising and open dialogue.	There is a need to dispel the notion that death should be the responsibility of healthcare providers. Caregiving, dying, death and grief are everyone's business. Simply informing people about matters relating to death, dying, or grief is not enough; compassionate communities empower individuals to act.	Compassionate communities provide the infrastructure that fosters conversations about death, raises social awareness, and creates supportive environments that empower action. Compassionate communities increase death literacy - the knowledge and skills people need to understand, access, and make informed decisions about end-of-life care. Using the arts to facilitate discussions of emotive topics is valuable and helps develop a compassionate culture.
On the island of Ireland, we must recognise, support and sustain initiatives that are driven by the community.	While service-led compassionate communities initiatives are the norm, community-driven, bottom-up approaches are more effective in fostering long-term sustainability and scalability. Many individuals may not recognise that their actions align with the compassionate communities movement —these initiatives must be identified and celebrated.	People with lived experience of caregiving, dying, death, and grief are uniquely positioned to identify unmet needs—we must empower people within our communities to recognise the significant value their lived experience can bring. Evidence shows community-driven initiatives are being delivered across our island—we must ensure the right environment for their continued growth. Building bridges between formal healthcare systems and community initiatives strengthens the capacity of groups and develops continuity of compassionate care.
A considered community development approach is essential, to ensure local voices and needs are prioritised and sustainable change is achieved.	It must be recognised that no single 'best example' exists for a compassionate communities initiative—communities differ in their assets, such as people and organisations, and also in what they lack. Organisations often struggle to hear the voice of the community when they do not know how to engage. If initiatives are not community-driven, organisations must engage at the right level and prioritise community voices. Unsettled times may reduce mental commitment to compassionate communities, and those willing to engage face barriers such as resource limits, inadequate support for complex care needs, and care system complexities.	Communities across the island of Ireland possess valuable strengths that we can leverage to develop compassionate community initiatives. Communities can develop initiatives by recognising unmet needs. To support this, we must amplify local community voices, particularly those with lived experience of caregiving, dying, death, and grief. Ensuring meaningful and sustained community engagement is essential to fostering compassionate communities that lead to real, lasting change across our island

KEY FINDINGS	CHALLENGES	OPPORTUNITIES
Inspiration and practical guidance are necessary to mobilise existing communities on the island of Ireland to develop compassionate initiatives.	Communities can lack both inspiration and practical guidance on how to begin building their own compassionate communities initiatives.	Communities can drive change themselves—there is untapped compassion across our island and a wealth of community assets. We must highlight that ordinary people can make a difference together and share examples of grassroots compassionate community initiatives. There is significant learning to be mobilised from individuals and organisations identified throughout this position paper, and many others, who have developed and delivered compassionate community initiatives.
Engagement from civic society across the island of Ireland is needed, to embed policies and support around caregiving, dying, death and grief within all our key institutions.	Civic society must engage beyond the context of health and social care. This is critical to ensuring compassionate support is available to people affected by serious illness in all aspects of their lives. We must recognise how interactions between individuals, communities, and their broader social environments influence care and support for those facing serious illness, dying, death, or grief.	To date Derry-Londonderry is the only city on the island of Ireland to have developed a Compassionate Cities Charter, offering an opportunity for local councils North and South to lead in prioritising compassionate support for caregiving, dying, death and grief in all key institutions. The Compassionate Civic Charter and the Bern Declaration 2024 provide a systematic approach to engage all sectors of society. There is opportunity for closer collaboration between government departments to support the expansion of programmes which have started in libraries and schools (Compassionate School Communities) and to look for other opportunities for partnership working.
Strategic leadership and investment is essential to foster compassionate communities across the island of Ireland.	Currently, no organisation has the resource to support a compassionate communities network across the island of Ireland or to provide vital strategic leadership. Many existing compassionate communities initiatives across the island face significant challenges with either a complete lack of, or short-term funding, which limits their sustainability and potential reach.	The Northern Ireland Regional Palliative Care in Partnership Programme includes a priority to develop a new public health approach to palliative and end-of-life care, and the new National Adult Palliative Care Policy (2024) in Ireland explicitly references compassionate communities. Investing in an organisation to provide strategic leadership for a compassionate communities approach is also in line with wider health policies and the evolving Programmes for Government. There is political goodwill for cross border co-operation within healthcare and public health, with significant opportunity to develop compassionate infrastructure while thinking in cross-border terms. Though compassionate communities initiatives have evidenced impact without financial backing, provision of funding to support the initiation, maintenance and evaluation of grass-roots initiatives can help the growth of a compassionate communities culture across our island.

Recommendations:

Caregiving, dying, death and grieving should not be the responsibility of health and society care. As such, it is our position that to deliver on the below recommendations, a clear mandate for fostering compassionate communities is needed from local government both North and South, with the recommendations translated into specific actions and delivered through relevant government departments.

The below recommendations are grounded in the principle that people with lived experience and communities themselves must be at the heart of delivering on all initiatives.

1. **Advocate for the adoption and implementation of this paper's recommendations by engaging with local government, government departments, councils and civic leaders**
2. **Support/establish an organisation with secured funding for at least five years to provide strategic leadership and act as a knowledge broker for compassionate communities across the island of Ireland**
3. **Deliver public awareness campaigns around the concept and benefits of compassionate communities, linked to providing recognition and reward to existing initiatives**
4. **Commission and complete an asset-mapping exercise to identify compassionate communities initiatives and community groups with potential to deliver initiatives across the island of Ireland. The results should be published in a publicly accessible online map and updated every six months**
5. **Facilitate engagement workshops in communities across the island of Ireland, to identify local need and establish partnership working between communities and health and social care.**
6. **Provide seed funding and mentorship for community groups to work in partnership with health and social care, to develop, deliver and evaluate impact of localised compassionate communities initiatives**
7. **Support the development of compassionate communities of practice, to share and to mobilise learning from existing compassionate communities initiatives**
8. **Establish steering groups for the development and delivery of compassionate civic charters in council areas both North/South**
9. **Commission research to support a 'roadmap' for fostering compassionate communities across the island of Ireland, focused on understanding local need, understanding what has worked for whom, where, and in what circumstances, and embedding best practice internationally**

We do not present this position paper as a definitive guide to what will be needed in the years to come to develop compassionate communities across our island. Rather, we hope this paper will serve to increase engagement in the need for compassionate communities and outline the critical steps which need to be taken at this point in time to support the development of a more compassionate approach to caregiving, dying, death and grieving.

Report structure

Methods: Brief summary of the sources of data that have been used to reach the positions presented in this paper.

Context: Overview of what makes a compassionate community and the relevance of compassionate communities to the island of Ireland.

Key findings: Synthesis of the key findings from the conference and progress to date in fostering a compassionate communities approach across the island of Ireland, including both challenges and opportunities.

Conclusions and Recommendations: Summary of the position paper and recommendations for fostering compassionate communities across the island of Ireland.

To cite this report please use:

Graham-Wisener, L., Crawford, S., & Crowe, A. (2025). Fostering Compassionate Communities: A Call to Transform Caregiving, Dying, Death and Grieving on the Island of Ireland [Position Paper]. Accessed via; https://professionalpalliativehub.com/events/past-events/compassionate-communities-in-palliative-and-end-of-life-care-conference/

METHODS

This position paper is based on outcomes from the *Inaugural Compassionate Communities in Palliative and End of Life Care Conference* (9th September 2024, Canal Court Hotel Newry) alongside expert stakeholder consultation. There were 120 conference attendees representing various sectors, including religious, education, voluntary, health care and local authority, as well as members of the public and individuals with lived experience of caregiving, dying, death and grief. Participants came from across the island of Ireland.

The following sources of data have been used to reach the positions presented in this paper.

I) On conference registration, conference attendees were asked to share details of any projects they are involved in which aim to support people with life-limiting conditions or people dealing with dying, death, and grief in the community

II) Researchers attended the conference and made observations on critical progress of compassionate communities to date. This included considerations of what is going well, what is not going well, what are the gaps, and what is needed.

III) A roundtable discussion was conducted at the conference informed by the nominal group technique. The roundtable discussion was open to all registered participants of the conference and involved a roundtable discussion across 11 tables. At the roundtable discussion two questions were posed by a facilitator. These questions were "What types of initiatives do you think should be prioritised to develop a compassionate response to caregiving, dying, death and grieving on the island of Ireland?", and "How do you think communities could be supported to develop initiatives around caregiving, dying, death and grieving?". Through a number of stages, individuals provided a response to each question and then responses were prioritised by the table.

IV) Expert stakeholders (n=17), with lived and professional experience, were consulted via four workshops during November 2024 to ensure completeness of the report and refinement of recommendations. This included individuals from the AIIHPC Voices4Care, from across the specialist palliative care sector, from community groups and organisations, and from policy.

COMPASSIONATE COMMUNITIES

The *Compassionate Communities* approach emphasises that caregiving, dying, death, and grief are shared responsibilities of the whole community. It champions a social model of care, encouraging communities to come together in supporting those facing the challenges associated with serious illness. This approach complements rather than replaces formal health and social care services, ensuring continuity and quality of care by empowering individuals and groups to provide practical, emotional, social, and spiritual support. By normalising what are universal experiences, compassionate communities challenge the perception of death as solely a medical issue. Instead, the community is actively involved in caring, with support from health and social care services when needed.

"Death is not the opposite of life, but a part of it".

HARUKI MURAKAMI

We will all experience dying, death and grief. Yet on the island of Ireland today, we often fail to recognise or acknowledge these realities. While death and dying are natural and universal processes, many feel that families and communities have been pushed to the margins in favour of clinical intervention and healthcare systems. This imbalance encourages society to view death as a medical event, neglecting the suffering that occurs between diagnosis and death, as well as the grief that follows.

The recent Lancet Commission on the Value of Death highlights this shift, calling for a renewed focus on family and community involvement and emphasising that death and dying are an essential part of life. Dame Cicely Saunders' concept of 'total pain' reminds us that suffering extends beyond the physical to include psychological, social, spiritual, and practical struggles [3]. Communities can address these broader aspects of suffering in transformative ways by spending time with the dying, sharing laughter and tears, offering practical support, and simply showing compassion and care. Communities are uniquely placed to support each other through the entire journey of serious illness, dying, death and grief. In doing so, communities can help individuals live as fully as possible, right until the end.

The 95 percent rule [4], as identified by Prof Allan Kellehear (Northumbria University), states that a person living at home with a serious illness may only come into contact with healthcare professionals up to 5 percent of any day. As a community, what can we do to fill that other 95 percent with care and connection?

This critical question has inspired the development of 'compassionate communities'.

Caregiving, dying, death and grieving as everyone's business

The compassionate communities movement recognises that caregiving, dying, death and grieving are everyone's business. The approach advocates for a rebalancing of roles, where healthcare professionals support families and communities, rather than taking the leading role [5]. It is about respecting that individuals and communities know best what they need. The compassionate communities approach highlights that death is inherently relational and proposes a social model of care in which communities mobilise social networks, or "circles of care", to support individuals approaching the end of life [5]. This could, for example, be a group of neighbours who organise to support people in their area living with serious illness. Crucially, these circles of care are composed of both informal and formal support, ensuring continuity and high-quality care. We recognise that healthcare organisations do not bear sole responsibility for end-of-life care, and we should not desire them to.

It takes a village to raise a child- this is an African proverb we often use on the island of Ireland. It also takes a village to care for the dying and the grieving.

A New Public Health Approach

Compassionate communities are a new way of thinking about dying, death and grief, informed by the new public health approach; the idea that we all share a responsibility to care for each other physically, emotionally, socially

and spiritually [6]. In this approach, communities work together to build their own capacity and skill in order to support people with serious illness at home, leaning on values like solidarity and personal agency. This support also extends to caregivers—family and friends—who often carry the greatest load in providing care [7].

By coming together, compassionate communities tap into collective compassion—a powerful, often-overlooked resource within communities that brings people closer, creating a network of integrated care and support for those who need it most [8].

Empowering Communities

At the heart of compassionate communities is the idea of empowering everyone to take action when it comes to serious illness, dying, death and grief [6]. This approach not only normalises these experiences but also shifts expectations around how death is managed and understood.

In a compassionate community, those with lived experience of caregiving, dying, death and grieving, are seen as valuable assets who understand what is needed to transform care for others. Their insights and experiences are essential in shaping the support systems that benefit everyone. Communities are encouraged to take the lead in providing care for their members at the end-of-life, with health and social care staff offering support and professional expertise where needed [9]. Working together by harnessing and connecting the skills and resources that exist in every community already (community 'assets'), compassionate communities can create an environment where individuals feel supported, understood, and empowered to support each other during life's most challenging moments.

Through harnessing community assets, compassionate communities offer opportunities and experiences that improve death literacy for their members, which is a vital component of how communities are able to support each other through caregiving, dying, death and grief. Death literacy is the knowledge and skills that enable us to engage in an informed way around issues relating to caregiving, dying, death and grieving. For example, someone who is death literate will be able to use their knowledge and skills to support an individual who is recently bereaved, or to provide practical support to a dying person.

Evolving Definitions and Frameworks

The compassionate communities movement is continually evolving and does not lend itself to a single definition. A commonly agreed understanding is that compassionate communities are;

"*Communities that invest in and promote individual behaviour, group strategies or societal structures or policies that prevent or reduce suffering resulting from experiences of serious (mental or physical) illness, death, dying and loss; actively promote health and well-being, community support and empowerment of community members affected by such experiences; and actively acknowledge these experiences as natural parts of daily life*" [6,10]

Compassionate communities encompass a variety of different initiatives[11], reflecting the diversity of different communities. Compassionate communities initiatives are therefore unique as the evolving needs of every community are different. Based on their needs, compassionate communities include time-limited initiatives as well as continuous activity.

While formal health services have initiated many initiatives (i.e. a top-down model), communities themselves have also developed examples of initiatives (i.e. the preferred bottom-up model). Regardless, it is crucial that compassionate communities are anchored in a community development approach. It is proposed that higher levels of community engagement are required for increased empowerment, which in turn enhances health and wellbeing[12].

Key elements within compassionate communities initiatives include[13]:

- the provision of space and opportunity for discussion on dying, death and grief;
- community engagement and social actions driven by conversation on grief, end-of-life, and death literacy;
- support for those who are dying while living at home, and their carers, from formal volunteer programmes (or alternatively referred to as 'activated citizens');
- improved capacity for care and support to be provided by mainly community members, for people at the end of life;
- the continuation of social relationships for those living with grief, post bereavement [13]

Compassionate communities and compassionate cities working together

A new approach called the "palliative care new essentials" has been proposed to improve care for people nearing the end of their lives and their families. This model highlights four key elements needed to ensure quality and continuity of integrated care in the community: i) specialist palliative care, ii) generalist palliative care, iii) compassionate communities, and iv) civic end-of-life care (which we can think of as compassionate cities) [14].

Compassionate communities focus on local neighbourhoods, like a suburb or village, to bring people together and support one another. In contrast, compassionate cities operate on a larger scale, aiming to engage local governments and institutions to make broader, systems-level change. This includes involving different parts of the community, such as schools, workplaces, and trade unions, to improve the social and physical environments we live in. The goal is to create a culture of kindness and support, leading to positive changes in how we care for each other. This transformation is guided by the Compassionate Cities Charter, and helps strengthen compassionate communities[15]. When fostering a compassionate communities approach, this systems level change is essential alongside developing community capacity.

Compassionate communities as a global movement

Compassionate communities are an expanding movement, currently present within at least 19 countries around the world [16, 17]. In Europe, compassionate communities can be found in Austria, Spain, Sweden, Germany, Poland, Portugal, the UK, and in Ireland [16]. In the UK, Compassionate Communities UK serves as a network organisation, providing a community of practice for individuals and communities developing compassionate communities initiatives. The scope of these initiatives varies, with many connected to the hospice network.

Specific examples of compassionate community approaches in England include; school engagement with hospice [18], health professional mentors who towards the end of someone's life can map what support is available and slot into areas of need to provide extra support [19], and training for volunteers from the community in how to support and care for the frail and vulnerable [20]. So why are compassionate communities important to the island of Ireland?

THE RELEVANCE OF COMPASSIONATE COMMUNITIES TO THE ISLAND OF IRELAND

Fostering a compassionate communities approach across the island of Ireland could be pivotal in addressing the key challenges we face related to caregiving, dying, death and grieving.

Our changing demographic profile

People on the island of Ireland are experiencing caregiving, dying, death, and grief, now more than ever. We are witnessing a rapid ageing of our population both North and South, with the number of people aged 65 and over projected to increase by more than half over the next 30 years [21, 22]. Associated with this, a growing proportion of our population will be living for longer with serious illness and multi-morbidity [1, 2]. Over time, these demographic changes contribute to a steadily rising death rate [23]. As caregiving, dying, death and grieving become even more commonplace within our society, we need to build more connected, resilient communities that are better equipped to face these challenges together. By encouraging collective compassion and connectedness, compassionate communities can help ensure that no one faces these profound challenges alone.

Alongside our evolving demographic profile, is a shift in place of care. Over two-thirds of people on the island of Ireland would like to be cared for and die at home [24, 25]. While this desire is not currently a reality for most [25], projections suggests home deaths will rise significantly between now and 2040 [1, 2]. Dying at home can represent an aspect of a 'good death', however not every home death is a well-supported experience. Achieving a 'good death' at home requires sufficient support for carers, effective coordination with healthcare professionals, and the active involvement of the wider community [26]. A compassionate communities approach can help to ensure that families have the support and confidence needed to make a good home death a more achievable option.

Inequality at end-of-life

We have many diverse communities across our island, and unfortunately, we know that not everyone has equal access to palliative and end-of-life care. One key source of inequity is geographic location [27], where one third of our population are living in rural or remote areas. In these areas, the burden of serious illness and caregiving is particularly pronounced due to an older demographic and higher levels of unmet healthcare need [28, 29]. For children requiring end-of-life care living in rural or remote areas, there is only one children's hospice in the Republic of Ireland [30] and only one in Northern Ireland [31], and so their access to this service is limited. Existing health inequalities are exacerbated at the end of life. Individuals in rural areas are more likely to be engaged in caregiving than their urban counterparts [32], yet limited access to respite and the necessity of traveling over 90 minutes to reach hospitals can place immense strain on these individuals [32, 33].

A compassionate communities approach helps address inequalities at end-of-life by mobilising local resources and support networks that are closely attuned to unmet needs. Often, this involves identifying and addressing place-based unmet need. The result is empowering entire communities to provide support to both the individual with serious illness and the family, while caring or bereaved.

Social isolation & loneliness

Social isolation and loneliness pose significant challenges for people living with serious illness across the island of Ireland, compounded by the growing number of people living alone [23, 34]. Research with palliative and end-of-life care professionals in Northern Ireland highlights that individuals with serious illness face a particularly high risk of loneliness [35]. This group is uniquely vulnerable, as they

experience multiple risk factors for loneliness, including advanced age, declining physical abilities, and often financial insecurity.

Many in our communities have limited social contact, with some people with serious illness interacting only with the healthcare professionals who provide their care. One healthcare professional spoke about a conversation with a patient in the community, where the person had reflected: "*You're the first person who's sat on that sofa in 12 months*" [35]. This isolation is often shared by informal caregivers, who find themselves without the time or energy to maintain social connections. The emotional toll of this isolation underscores the urgent need for a compassionate communities approach to foster social connection, as advocated for already in a Marie Curie Northern Ireland report on loneliness [35]. A compassionate communities approach nurtures relationships through neighbourhood and community networks, providing a sense of security and belonging. For example, the Compassionate Communities Connectors programme in Australia which trained community volunteers, evidenced that the initiative was able to address gaps that formal service could not and particularly for those who lived alone, or were socially or geographically isolated [36, 37].

"When you lose someone you love, your life becomes strange, the ground beneath you becomes fragile... However, you are not alone." JOHN O'DONOHUE

Unmet emotional and spiritual needs

Loneliness is only one of many emotional challenges that those living with a serious illness and their caregivers face. Serious illness can increase risk of psychological distress, anxiety, and depression [38]. Caregivers, who often provide more than 43 hours of unpaid care each week, are also at heightened risk of poor mental health outcomes [39]. Indeed, findings from a longitudinal study in Northern Ireland report both caregivers and those

grieving the death of loved ones are up to 50 per cent more likely to face mental health problems than those not in caregiving roles [40].

Public health models of mental health and bereavement support, such as the four-tiered bereavement model [41], recognise that most individuals can cope with serious illness and grief through support from their social networks, without the need for specialist mental health intervention. A compassionate communities approach is central to ensuring that those facing serious illness, caregiving, or grief have access to this crucial social support. Indeed, some argue that we should reconfigure stepped care models to recognise that community support is the central component within the system. By mobilising informal care systems within the community and establishing a firm foundation, compassionate communities reduce the need for specialist services, helping individuals manage grief and mental health challenges in familiar, supportive environments. By embedding care within the community, compassionate communities create environments that buffer against the mental health impacts of caregiving and bereavement.

Need for cultural change around death and dying

Across the island of Ireland, death and dying are not routinely discussed within our communities. Various barriers exist to engaging in 'death talk', including a perceived lack of social acceptance or a fear of upsetting others [42]. One consequence of this is that only a minority of people have engaged in advance care planning [43]. Advance care planning is an ongoing process that supports adults of any age in sharing their values, goals and preferences regarding future medical care during serious and chronic illness [44] and is evidenced to positively impact the quality of palliative and end-of-life care [45]. In acknowledging advance care planning as a continuous process across the life course, we need to upstream conversations about death and dying.

Compassionate communities encourage open dialogue about dying, death and grief. They do this by creating a more supportive and understanding environment, where individuals feel more comfortable discussing and planning for end-of-life. This could be key to supporting wider engagement in advance care planning across our island, towards helping to deliver end-of-life care in line with individual goals and values.

Increased demand for palliative and end-of-life care

Although the need for a compassionate communities approach is broader than addressing the increasing demands on specialist and generalist palliative care services, by empowering communities to take ownership of dying, death and grief, this is likely to reduce reliance on overburdened health services.

Due to our changing demographic profile, it was estimated that between 2015 and 2046 in the Republic of Ireland, there will be an increase of 84 per cent in the number of people who will have a palliative care need (based on their disease) [1]. This means that Ireland will need almost double the provision of palliative care in only 30 years' time [1]. This is a considerable problem – how can access to, and quality of, palliative and end-of-life care services be improved, and quickly?

Investment in a compassionate communities approach would reform the model of care, so there is a less significant need to scale up current service provision. With an upstream focus on the population, it could ensure longevity and sustained change in how serious illness, dying, death and grieving are supported across the island of Ireland [6]. There is evidence of cost-savings to the health service from compassionate communities initiatives [14], where initiatives have demonstrated a reduction in unplanned admissions to hospital and fewer unscheduled visits to primary care and other allied health services [11, 46, 20]. For example, a compassionate communities initiative in Frome (UK) evidenced a 14% decrease in unplanned hospital admissions during the four-year study period [47]. In Australia the savings from delivery of the Compassionate Communities Connectors programme were reported at $518,701 AUD over 6 months, where they assumed enrolment of 100 patients [48]. Compassionate communities may also be a cost-effective choice for the patient and their families within the health system through less of a reliance on privatisation of care [49].

COMPASSIONATE COMMUNITIES AND NATIONAL POLICY

A strategic challenge for our shared island

Across the island of Ireland, we share in the challenges surrounding caregiving, dying, death and grieving. There is existing North/South policy alignment in the development of compassionate communities, as detailed below.

The establishment of compassionate communities and cities presents a strategic opportunity for North/South cooperation, which resonates closely with the broader aspirations of the Shared Island Initiative, working both within and across communities to build a more inclusive society. This approach seeks to bring those experiencing challenges around the end-of-life back from the margins. Numerous areas of North/South health cooperation have already demonstrated significant value, such as the North-West Cancer Centre in Altnagelvin, Derry-Londonderry. The *Inaugural Compassionate Communities in Palliative and End of Life Care Conference* which serves as the foundation of this position paper, was funded via the Shared Island Civic Society Fund, demonstrating the strong cross border dimension. Additionally, the Shared Dialogue Series on 'Working together for a healthier island' has underscored the potential for deeper collaboration in public health.

To build a truly healthy island, addressing suffering at the end-of-life must become an integral component of our public health approach. Investment in the development of compassionate communities is one key mechanism to deliver a better quality of life and death for all residents of our island.

Northern Ireland

The development of compassionate communities has been increasingly – if not explicitly- aligned with palliative and end-of-life care policy in Northern Ireland, making this an opportune time for committed focus. The evolving Programme for Government (2024-2027) recognises the need to transform the health and social care system through service reform and reconfiguration. Investment in compassionate communities would help increase capacity within health and social care and would address calls to deliver in innovative ways for communities across Northern Ireland.

The Regional Palliative Care in Partnership Programme, established in 2016, supports the delivery of quality palliative and end-of-life care across settings in Northern Ireland. One of four priorities of this programme (2023-2026) is 'Public Health Approach to Palliative Care'. However this programme is working to deliver on the *Living Matters, Dying Matters* strategy which, although emphasises the need for development of palliative and end of life care within the wider public health agenda, does not provide a specific mandate for developing a compassionate communities approach. The Public Health Agency has however provided funding for Compassionate Communities NI, a network of cross-sector organisations and individuals who develop a response to the challenges regarding end of life in all communities.

Investment in compassionate communities contributes to the ambitions of the new Northern Ireland Advance Care Planning Policy, by providing a context for more 'upstream' conversations around end-of-life and by providing a more comprehensive 'circle of care' through which end-of-life wishes can be realised.

The Department of Health Strategic Planning and Performance Group Health Service Executive in Northern Ireland is currently implementing a framework for an integrated care system. This framework aims to establish collaborative working across health and social care services and others such as local councils, service uses, carers and the community and voluntary sector to improve health and wellbeing and reduce recognised health inequalities. The complimentary vision of this framework to that of compassionate communities, suggests that establishing compassionate communities could provide the method for this framework to move forward.

Lastly, compassionate communities resonates closely

with broader health policy direction, such as Health and Wellbeing 2026: Delivering Together. This strategic plan recognises the importance of building capacity in communities and in prevention, including discussion of harnessing the existing assets within communities.

Republic of Ireland

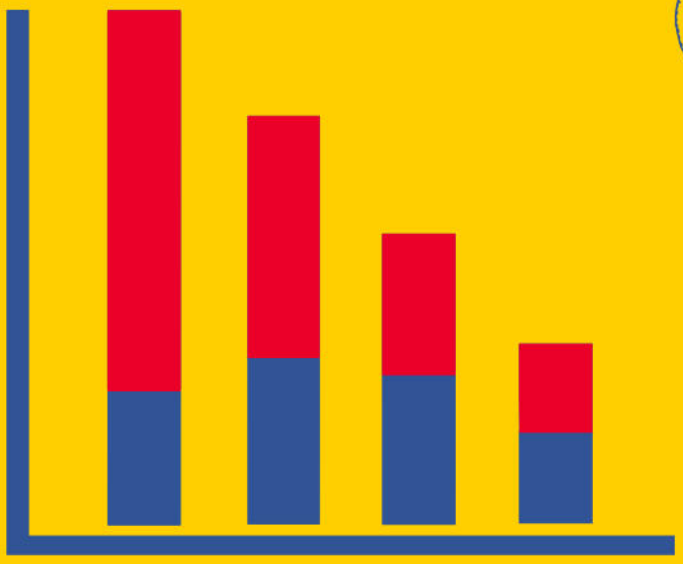
As with Northern Ireland, compassionate communities have been consistently aligned to palliative and end-of-life care policy across recent years. The 2020 Programme for Government emphasises the need to deliver more care in the community, with a particular emphasis on supporting older people to live in their own home with dignity and independence, for as long as possible. Investment in compassionate communities would help to deliver the continuity of care and place-based support needed to enable this policy objective.

The new National Adult Palliative Care Policy was published in September 2024, explicitly recognises the need to integrate a public health dimension into palliative care. The policy includes a recommendation to support the development of compassionate communities. The activities associated with the recommendation include;

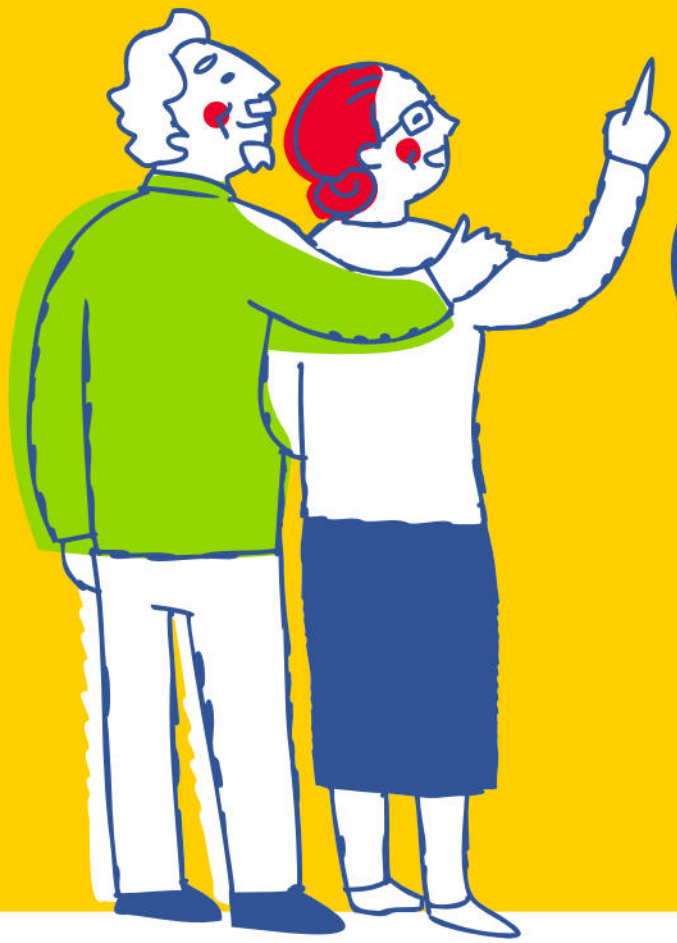
- Engage across Government Departments and agencies with the aim of empowering local government to mobilise available resources to address local needs for palliative and end-of-life care.
- Identify, evaluate, and implement exemplar models of community action in palliative, end-of-life care, and bereavement through competitive applications to the Sláintecare Healthy Communities Programme.
- Implement community development programmes in Regional Health Areas so that local citizens and specialist palliative care providers develop initiatives that build community action in palliative, end of life care and bereavement

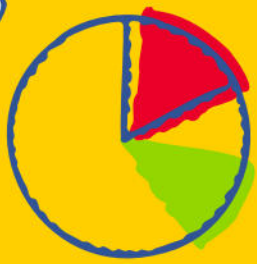
The updated policy was preceded by various frameworks, such as the Adult Palliative Care Services, Model of Care for Ireland by the National Clinical Programme for Palliative Care, which emphasised the importance of a public health approach where the community are viewed as an equal partner in the task of providing quality healthcare. Compassionate communities were explicitly referenced as an example of the public health approach in action within this policy, in the form of the Milford Care Centre in Limerick [9].

Launched in 2021, the Sláintecare Strategy, aims to recentre Ireland's health care system to provide the majority of care within the community, in turn reducing health inequalities. The strategy also extends the work of the Healthy Ireland Framework 2019-2025, initiated in 2013. The Healthy Ireland Framework aims to work collaboratively across government departments and civic partners to empower individuals and communities to manage their own health and wellbeing. This strategy echoes the compassionate communities movement which also aims to make accessible community care a reality.



KEY FINDINGS FROM THE CONFERENCE





CURRENT PROGRESS IN DEVELOPING COMPASSIONATE COMMUNITIES ACROSS THE ISLAND OF IRELAND

We have established that there is a need to improve end-of-life and palliative care in the community, and that this is a priority in both Northern Ireland and the Republic of Ireland. Compassionate communities have been referenced as a vital part of developing our public health approach to palliative and end-of-life care, both in national policy and within consultation exercises[50, 51, 52]. The conference plenary sessions and discussion further evidence the necessity of investment in compassionate communities and cities, as a strategic driver for delivering this broader public health agenda.

The following section provides a synthesis of the key findings from the conference and reflects progress to date in fostering a compassionate communities approach across the island of Ireland, including both challenges and opportunities.

FINDING Compassionate communities initiatives need to be recognised as creating the environment for meaningful education, social awareness raising and open dialogue.

The importance of compassionate communities for creating the conditions for meaningful public education, social awareness raising and open dialogue around death was a recurring theme throughout the plenary sessions and roundtable discussions at the conference. Globally, these are central goals of many compassionate communities initiatives, serving as a crucial foundation for mobilising community action [53]. Compassionate communities and compassionate city initiatives create supportive environments for discussing dying, death and grief. By fostering partnerships and engaging communities, this approach ensures that people are not only informed but empowered to act.

Building a compassionate infrastructure

Sharon Williams is the Project Manager at Compassionate Communities NI, which was established in 2015 and has two hubs; in the Northern and North West localities. Compassionate Communities NI is a network of cross-sector organisations and individuals who develop a response to the challenges regarding end of life in all communities. Sharon spoke about how without openness and recognition of serious illness and death in the community, we risk leaving people alone, isolated – and this social isolation is a significant problem. Through compassionate communities initiatives, conversations about death can start to happen, so preventing what she described as a *social death*.

"*Dying over the last 50 years has happened predominantly in acute settings, and in nursing homes, and therefore we have lost the meaning in death. As a result, many of us feel disempowered to offer emotional and practical support. Sadly, this leaves those dealing with failing health and advanced illness, feeling socially isolated and lonely. And this social death is also experienced by our unpaid carers, and those living with bereavement*" (Sharon Williams, Compassionate Communities NI)

Sharon described the focus of Compassionate Communities NI in creating a *compassionate infrastructure* to increase death literacy. We know from previous research that there is opportunity to increase death literacy in communities across our island. We have untapped compassion within our communities- people want to know how to do better when someone is dying or grieving.

Sharon spoke to the achievements of Compassionate Communities NI in recent years, including the advantage of cross-sector working to co-develop events and educational resources between community and clinical staff. One initiative is the Compassion in Action Programme, which through workshops raises social awareness of how people can help each other and the impact of small acts of kindness. Partnership working has been at the core of all initiatives, some of which have included creating spaces for open dialogue about death within the community. One example is Death Positive Libraries, where an expanding list of libraries across Northern Ireland, and most recently in Cavan, have curated selections of books, articles and resources on a range of topics related to death and dying and, hosted death positive book clubs. Some libraries have also hosted workshop events such as 'Understanding Grief', have hosted a Before I Die wall, and have offered opportunities for people to connect with local support groups and services. This provision of space was also identified in the roundtable discussions as valuable for supporting development of compassionate community initiatives.

If we can work culturally, we can achieve so much

Sharon also emphasised the power of the arts for engaging the public in what can be a highly emotive topic. This was also a key message from Dominic Campbell, who has led the Irish Hospice Foundation's Arts and Cultural Engagement Programme since its inception in 2020. Dominic emphasised that in order to grow compassionate communities, we need to consider investing in and nurturing compassionate culture. Dominic described how working within the current culture of the community was crucial. Culture can include "language, ideas, beliefs, customs, codes, institutions, tools, techniques, works of art, rituals, and ceremonies, among other elements". Dominic referred to Prof Kellehear's reference to there coming a point in all of our lives when everything changes. We need to create a way through that, and we need to do that at scale. The global movement called 'arts in health' is trying to put together those tools for people.

"*In times when the narrative of life is broken, when you are bereft, people reach for arts and culture. For the manifestation of arts and culture. For all sorts of creative tools to help you navigate a journey of the spirit and of your community, and a time that is uncertain*" (Dominic Campbell, Irish Hospice Foundation Arts and Cultural Engagement Programme)

The Arts and Health Engagement Programme is informed by the IHF People's Charter on Death Dying and Bereavement, which aligns to a public health approach to palliative and end of life care. Dominic described how the programme's delivery mechanism starts with creativity and experimentation - getting people curious- and then moves into communication and education. Among developments has been investment in place-based community development (the Compassionate Culture Network), with a call for a healthcare professional and artist to develop a bespoke programme for their local community around exploring death and grief. This approach includes looking at the assets that are available in every single community, with the intention in Dominic's words to 'animate the culture' - make it normal to have conversations about dying, death and grief .

One of nine networks established to date has been in Buncrana, Donegal, led by visual artists Rebecca Strain and Martha McCullogh. Rebecca discussed how they worked with a small community group to deliver creative sessions including paper making, camera-less photography of special objects, and writing workshops - all exploring death and grief but in a gentle way. They started a Make 'n Mend Facebook group, for anyone not able to attend sessions but who would like to find creative ways to navigate grief. In these groups there was never any pressure to do anything, community members could just sit and chat. These arts-based initiatives didn't have agendas, and what developed was genuine community, and acknowledgment of grief in that community.

> *"I want to use art to help people to deal with things that they maybe can't talk about, or don't have the words for. And use it as a way of transforming"*
>
> REBECCA STRAIN, VISUAL ARTIST IN BUNCRANA, DONEGAL

Through the roundtable discussions, art was raised as being something of value when developing compassionate communities. Dominic also described the importance of place-based programmes- acknowledging that services are universal but not necessarily local. He emphasised the importance of accompaniment- having someone with you to navigate those moments when your life changes.

Opportunities for development

It was evident throughout the conference that a challenge is that there is a need to enhance understanding and awareness of caregiving, dying, death and grief. Encouraging people across our island to engage in conversations and learning experiences about death is essential and can improve our island's death literacy. Compassionate communities can create the supportive environment needed to not only inform but also empower people to take action.

The importance of raising social awareness about how compassion can be harnessed within communities was highlighted, as was the need to mobilise the compassionate communities movement across the island. This involves, as raised during the roundtable discussions, dispelling the notion that death and dying are matters solely for healthcare professionals. The need to work culturally was emphasised and recognising what that means for different communities across Ireland.

From the conference roundtable discussions, there were several good examples suggested which would assist in improving understanding and conversation about death. These included facilitating 'death conversations' in community settings, education on death and dying across the life course (including to children in schools) and initiatives broadly focused on improving death literacy.

The Caru Project

The Caru project, led by the Irish Hospice Foundation, the All Ireland Institute of Hospice and Palliative Care, and the HSE, is a continuous learning programme that is offered to every residential home in the Republic of Ireland. The aim of Caru is to support and improve the delivery of compassionate, person-centred, palliative, end of life and bereavement care to residents and family members in nursing homes.

The Caru Project supports the whole community of a residential home including the residents, staff, families, friends and kinship groups.

Linked to the 5 year programme, the Irish Hospice Foundation are supporting a project which aims to support conversations on dying, death and grief in residential settings using creative arts.

Six artists have been paired to a residential home local to them where they deliver innovative approaches to explore how art can open conversations about death and grief. Through dance, song, film, drama, poetry or storytelling, the challenges and griefs connected with residential care are addressed.

"It just opened the floodgates. I am here nearly five years, and I have noticed a big difference through the arts...Talking through arts is a great thing to me I think, because sometimes when your hands are doing, your minds not thinking, so you just go on...."

ACTIVITY COORDINATOR

FINDING On the island of Ireland, we must recognise, support and sustain initiatives that are driven by the community.

The conference highlighted that across the island of Ireland, numerous grassroots initiatives have been initiated and led by communities themselves. A key takeaway was the importance of recognising, supporting, and sustaining these compassionate communities efforts.

Internationally, compassionate community initiatives have taken many forms, with most following service-led, top-down models 11. However, research suggests that community-driven, bottom-up approaches are often more effective in fostering long-term sustainability and scalability. These models empower communities to take ownership of care, initiating and delivering tailored responses to the unique challenges they face [12].

Sharon Williams highlighted the value of recognising existing community assets, particularly people with firsthand experience of caregiving, dying, death and grief. The community-driven initiatives described below have all been instigated by compassionate people living within our communities who recognised an unmet need and acted. They share a common thread- the projects recognise the power of lived experience within a network of care and the unique ability of the community to provide continuity of support. Prof Kellehear (Northumbria University) asserted in his address that true continuity of care is impossible without the active involvement of the community.

The power of lived experience

Eileen Pugh, whose husband Derek died four years ago, started M50 Soulfriends when she recognised the lack of space for people to openly discuss grief. Eileen shared how bringing together people who like her, had been widowed, created a profound connection based on shared experience. Initially organising small workshops, Eileen found that people were willing to travel long distances just to have a place to talk about grief. People wanted to be able to talk to others who had also lost their significant other, no one else understood what they were going through, and the events that Eileen organised where death and grief were simply talked about had immense value as a starting point.

"The profound transformation of people over even two days, over even three hours, is incredible. If they are with other people who get it"

EILEEN PUGH, FOUNDER OF M50 SOULFRIENDS

The M50 Soulfriends WhatsApp group was formed in 2022, with 12 original members, who came up with the idea over a dinner organised for widowed people. The WhatsApp group has now grown to 146 members. Eileen explains that anyone within the group can organise an event or activity and the community therefore manages itself. One of the members, Robert, who was recently widowed, talked of the significant gaps in care for people who are bereaved. Robert shared how vital it was to be part of a group who had gone through the same devastating experience;

"Everyone on it is like me. They have all lost their partners and are broken. They see the world in a totally different way. They have love and kindness to give. I breathe for the very first time in a very long time" Robert, describing his first experience of M50 Soulfriends

Like Eileen, Robert emphasises the lack of preparedness within communities to support widowed people. He describes how friends and family want to help, yet often don't know how. Robert highlighted a resource which has been co-developed by M50 Soulfriends, with input from another bereavement support group in the UK, to provide guidance to those wanting to support someone who has recently been widowed. In his presentation, Robert urged the audience to think creatively and explore new approaches to lessen the immense suffering experienced around end-of-life.

The community providing continuity of care

Another grass-roots project discussed was a WhatsApp group for parents and carers of children with a life-limiting conditions. Samantha Villena (known as Sam) founded the group and is mum to Alex (17 years old) and Isabell (13 years old), who has a rare neurological condition (Aicardi Syndrome). Sam founded 'Extra Special Kids' support group in 2012, a year after her daughter was born. During that year, Sam had encountered mums in a similar situation to herself and identified the need for an online community so they could provide support to each other. Starting with just 15-20 members, the group has grown to 150 members from across the island, offering a vital emotional support to parents and carers.

"A lot of it is pure emotional support, because we all get each other. The kids have such a variety of conditions, and there is always somebody there who is going to give you their experience and just say we're here for you. That's it, we're just here to listen to you" SAM VILLENA, FOUNDER OF EXTRA SPECIAL KIDS CLUB

Sam highlighted that whilst healthcare professionals are so appreciated, they are not available to listen to you all the time, but the community can. Online communities can be particularly useful for carers, who can find it difficult to meet otherwise around caring responsibilities. Sam describes the group as a very positive and caring place, which largely manages itself. Sam talked about the maintenance of the community over time, and how bereaved mums often stay in the community and give advice. This can be so valuable for mums who are newly bereaved, as they know there are people in the group who are ready to step in and offer their support on that part of their journey. At the roundtable discussions support for carers was highlighted as a priority in the development of compassionate communities.

Sam discussed the power of personal experience, and the impact of just knowing that someone has gone through a similar experience to yourself. You can only get that from people who have walked in the same shoes as you.

Sharon Thompson is a member of the group, and a bereaved mum to her daughter Victoria, who needed palliative care in 2012. Sharon added that the group has come offline too, with some members meeting in person. The group had recognised that there

was a need for activities for children with life-limiting conditions, who can sometimes find it difficult to attend camps and clubs. See below for more information about the 'Extra Special Kids' club for the children.

Sharon described how the evolution of the support group has involved many aspects of the compassionate communities initiatives discussed during the conference, and highlights the need to recognise, support and sustain initiatives that are driven by the community:

> *"This has all happened organically. And it is because people care, and want to support each other, and are showing compassion"* SHARON THOMPSON, MEMBER OF EXTRA SPECIAL KIDS CLUB

Developing links with healthcare professionals

A final example of a compassionate communities initiative was provided by Jaqueline Daly, co-founder of East Galway & Midlands Cancer Support. Jacqueline started the group after her husband was diagnosed with prostrate cancer and she recognised how little community support was available. Jacqueline described the journey of starting as a prostate cancer support group with no fixed premises, to establishing a support centre to provide a network of emotional, psychological and practical support to people living with cancer, their family and friends.

> *"Some of the things we have learned along the way are that it takes a village. It will never take one or two people to do what needs to be done"* JACQUELINE DALY, CO-FOUNDED OF EAST GALWAY & MIDLANDS CANCER SUPPORT

Jacqueline describes developing the project in line with unmet need in the community. The centre has 11 counsellors on board, offers numerous complementary therapies, and has built valued relationships with oncologists and consultants. This close relationship with the hospital is described as crucial and encompasses the majority of referrals to the centre. Jaqueline praised the work of Portiuncula's Nurse-led Oncology Unit, and described how the centre can support the unit by providing transport home for patients and their families after receiving bad news, and support the family to help put some sort of normality around the situation and make them aware of how they can be supported. The group recently bought a bus for trips to take members for radiotherapy sessions at Galway hospital. Jacqueline spoke about how this has inadvertently developed into a support group – a warm and positive space for people regularly making the journey. The centre also houses a gym and engages in supporting research projects where they can.

Jacqueline left the audience with a take home message - "*Those who say it can't be done are usually interrupted by others doing it*".

Opportunities for development

We know that compassionate communities initiatives are being driven by communities across the island of Ireland. Although it is clear that many of these initiatives developed organically, it is essential for us to foster the right environment that supports and encourages their growth. This includes empowering people within our communities to recognise the significant value that their lived experience can bring to the table. Many individuals may not fully realise that what they are doing aligns with the compassionate communities movement, nor understand the profound impact their actions have. It's vital that these contributions are recognised and celebrated, as they are integral to building compassionate communities. Health and social care professionals have a critical role in supporting these community-led efforts. By building bridges between formal healthcare systems and community initiatives (as has been demonstrated), they can help strengthen the capacity of these groups and ensure a continuity of compassionate care.

From the conference roundtable discussions, conference attendees suggested value in 'anything which would make people feel not on their own'. It was recognised that we need to expand our thinking to consider how compassionate communities can help achieve 24/7, continuity of care. The conference attendees emphasised the importance of peer support and of valuing lived experiences, and the need for support outside of healthcare settings (e.g. listening rooms for bereavement support). The importance of identifying existing compassionate communities initiatives to allow for signposting was also emphasised.

FINDING A considered community development approach is essential, to ensure local voices and needs are prioritised and sustainable change is achieved.

A clear message from the conference was that no compassionate community is the same. When asked for a 'best example' of a compassionate communities initiative, Prof Kellehear emphasised that "*every*

Extra Special Kids

In 2023, parents in Donegal decided to take the national online support group 'Extra Special Kids, Ireland' offline to create a club specifically for life-limited children.

The club is an informal group where parents communicate and arrange events with each other via a WhatsApp group.

Extra Special Kids provides a space that is too often unavailable for children with complex medical needs.

Through the club, children and their families are provided with a supportive environment where they can make memories to last a lifetime. The club engages in many activities including messy play, music therapy, coffee mornings, mothers meet-ups and come Christmas time, Santa videos.

"We created a community of parents of children with disabilities and complex needs so that we could provide a social and fun friendship experience for our gorgeous children who don't get to have the experiences that neurotypical children have. We also created this space so as carers and friends we have our "tribe" so we can support each other." A MOTHER OF A CHILD WHO ATTENDS THE CLUB

community is different, and so every compassionate community is different". He illustrated the diversity in how existing compassionate cities across the globe have developed; the compassionate city of Ottawa (Canada) was led by businessmen, the compassionate city of Bern (Switzerland) led by palliative medicine physicians, the compassionate city of Frome (England) led by the local primary care services and compassionate Seville (Spain) led by the church. Regardless of how they develop, it is essential to ensure that the voices of the community are front and centre. The direction provided from the conference was clear: compassionate communities are built when a community's voices are actively listened to and respected.

Voice and focus of compassionate communities

No two communities are the same. What one community has in terms of assets - the people who live there, organisations, and services - will be different from another community. The same is true for what a community does not have. Therefore, the unmet needs of every community are unique.

Compassionate community initiatives can be developed by whoever hears the voice of the community, recognises the unmet need and has the motivation to make a change. Jaqueline Daly from East Galway & Midlands Cancer Support is an example of how successful compassionate communities are built using the voice of a community. When Jacqueline's husband was living with prostate cancer, she was disappointed by the lack of dignity he received in his care and decided to address the issue head on for other people and families in the same situation. Upon doing so, other members of the community with similar issues came to Jacqueline for help. The community met regularly to voice what the unmet needs of the community were. This in-depth understanding of unmet need within a particular community informed the development of East Galway & Midlands Cancer Support.

During the conference, attendees recognised that it is difficult to hear the voice of the community when individuals don't know how to engage with community members. Alison Bunce, who is the programme lead for Compassionate Inverclyde, a compassionate community initiative based in Scotland, made numerous suggestions on how a community's voice can be encouraged and amplified. Such suggestions included developing a steering group with community members, holding 'listening events' where community members are simply asked what a compassionate community would mean to them, as well as holding public events and using social media to recruit volunteers. The importance of taking the time to engage with the community to listen to their voice was mirrored through the conference roundtable discussions. Conference attendees noted the importance of extending invitations to community members and organisations to both understand unmet need and to co-develop initiatives to address unmet need. It was also noted that every effort must be made to engage with people with valuable lived experience of caregiving, dying, death and grief as they can provide insight into what is missing, lacking or could be done better.

The answer of how to develop a successful compassionate communities initiative lies within the community itself. Listening to the voice of the

community provides a natural, grassroots starting point. If a compassionate communities initiative speaks to the heart of the community and gives people a belief in what they are doing, it will more than likely be sustained.

Developing a compassionate community requires time, patience, and trust. Alison Bunce shared that it took five years to fully realise the vision of 'Compassionate Inverclyde' and a full year just to launch. Building relationships, listening to various groups, and understanding their needs was essential.

"It didn't officially launch until 2017 and why? Because it was so important to hear the voice of the community. It was so important to build the relationships up in the community, to actually understand what does our people want, not want we think as professionals that they would like." (Alison Bunce, Compassionate Inverclyde).

FINDING Compassionate communities need active and systematic engagement

As discussed by Dr Guy Peryer (Director of Education & Research, St Christopher's Hospice), community engagement is essential to the success of compassionate communities. However, for engagement to be impactful, it needs to be both active and systematic. Firstly, engagement must be systematic as you need to identify organisations and individuals who can help build the compassionate communities initiative and plan how you are going to approach them. Secondly, the engagement must be active. Active engagement means using civic orchestration to build, bridge and link social relationships between the community, generalist services and specialist services.

Sharon Williams from Compassionate Communities NI, demonstrated how active and systematic engagement is behind the success of their compassionate communities initiatives. Compassionate Communities NI was formed by a cross-sector partnership between Compassionate Communities North West and Compassionate Communities Northern. The linking of the two organisations combined staff knowledge and skills to create a stronger collaborative effort to raise awareness across NI. Compassionate Communities NI has since identified and collaborated with various other organisations across NI to further enhance engagement. Sharon Williams discussed an example of an event that was held to engage women from farming families in succession planning, where Compassionate Communities NI collaborated with Northern Trust Rural Support and Ulster Farmers Union. The event was very successful, with people having to be turned away at the door. The building, bridging and linking of professional relationships has been essential for their work as the reach of the work of Compassionate Communities NI relies on community partners and champions.

> *"The project has been able to evolve and develop its scale, having a wider impact because of the partnerships and working with others."* (SHARON WILLIAMS, COMPASSIONATE COMMUNITIES NI)

Moving forward with collective action

Active and systematic engagement can be difficult in the current unsettled times. Dr Guy Peryer acknowledged that recent and ongoing world events, such as the COVID-19 pandemic, cost of living crisis and war in Ukraine, may mean that people are less able to mentally commit to engaging with compassionate communities initiatives. Additionally, those willing to engage often face barriers such as resource constraints, complexities in the care system, and inadequate support for diverse care needs. Overcoming these challenges requires collective action and collaboration. As Dr Peryer stated, *"If we're going to move forward, we need to move forward together."*

To move beyond the barriers, Dr Peryer recommended building systematic engagement. To build systematic engagement, communities need to identify the strongest existing relationships within them - *"start with what's strong, not with what's wrong"*. Dr Guy Peryer also drew upon Marshall Ganz's 'Power of Story' theory [54]. To encourage active engagement, it is important for people within a community to understand why me, why us, and why now? Once individuals understand the importance of their role, it is essential to equip the inner networks available to people when dying, since the best support comes to people from those who know them the best. Equipping these individuals will ultimately strengthen the community network, as a network is only as strong as its individual links. Dr Guy Peryer also gave a general example of what the structure of an engaged compassionate community could look like, with a core steering group- approximately eight people- at the centre, and several spin-off small groups dedicated to addressing certain unmet needs within the community, such as a group for the homeless.

Opportunities for development

Communities across the island of Ireland possess a wealth of strengths that – once identified- can be leveraged when developing compassionate communities initiatives. A strength-based approach is essential to recognising existing assets, while addressing unmet needs. In the roundtable discussions, conference attendees recognised that we have various community groups across the island

who could be supported – with the right capacity- to deliver compassionate communities initiatives.

Community engagement ranges across a continuum; from informing and consulting, through to co-production, collaboration and empowerment, with the latter aligned to building community capacity to identify and solve their own issues [12]. If compassionate communities initiatives are not instigated by community members themselves based on local need, organisations need to be aware of the level at which they are engaging with communities and ensure community voices are front and centre.

Working *with* as supposed to *in* communities requires appropriate time and resource, and there are opportunities for us across the island to ensure the voices of local community members are amplified. Ensuring meaningful and sustained community engagement is key to fostering compassionate communities that lead to real, lasting change across our island. The roundtable discussions frequently emphasised a need to create the opportunities for community engagement, through inviting communities to open forums to discuss local needs and potential solutions. There was also the suggestion to establish a publicly available database, detailing community assets and needs, to inform the development of compassionate communities initiatives in partnership.

FINDING Inspiration and practical guidance are necessary to mobilise existing communities on the island of Ireland to develop compassionate initiatives.

The conference was filled with enthusiasm and a strong commitment to making compassionate communities a reality on the island of Ireland. Expert speakers delivered positive and inspirational talks about the potential of these initiatives. However, from the questions raised and discussions throughout the event, it became clear that many attendees were seeking not only inspiration but also practical guidance on how to begin building their own compassionate communities initiatives. There was a clear desire for concrete steps to help turn this vision into actionable plans at the local level.

It begins with you

A key message from the conference was that the responsibility is on all of us to develop compassionate communities. Speakers throughout the event, highlighted the importance of not waiting for someone else to make the change and to make the change ourselves. It was clear that just getting started is the key. For example, starting to have conversations with organisations around the community, or as Eileen Pugh

Rosie's Trust

Rosie's Trust keeps people and their pets together.

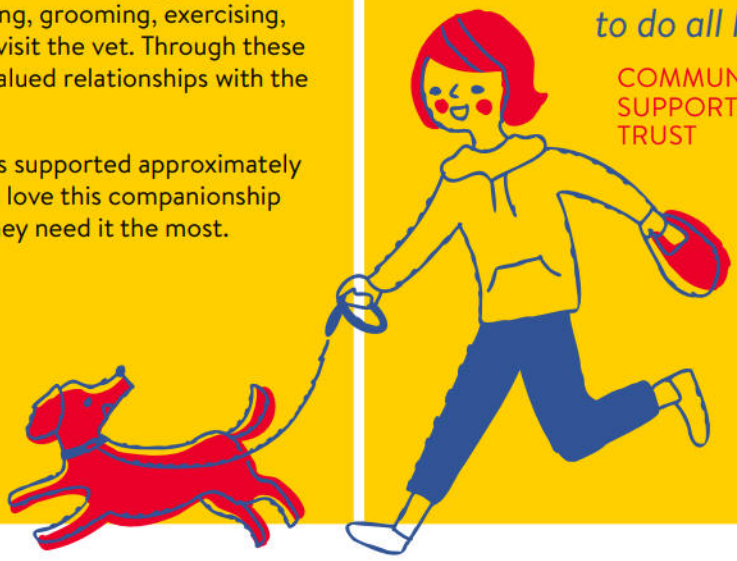
Rosie's Trust is the only charity in Northern Ireland that is dedicated to support people who may be receiving cancer treatment, end of life care or are elderly with a disability look after their pets.

Approximately 212 Rosie Trust volunteers visit people's homes 365 days a year to provide free support to care for their pets through feeding, grooming, exercising, playing and taking them to visit the vet. Through these visits the volunteers build valued relationships with the pet owners.

Since 2015, Rosie's Trust has supported approximately 217 people keep the joy and love this companionship brings to their lives when they need it the most.

"Rosie's Trust comes out to me and walks Finn every day – not for money or profit, but for a genuine love for my dog. Finn benefits so much from this and me too; I have peace of mind that he is getting what he needs while I'm not able to do all I can for him."

COMMUNITY MEMBER SUPPORTED BY ROSIE'S TRUST



from M50 Soulfriends did, simply find a venue, advertise on social media, and invite people to meet to talk about grief.

"I then set about trying to gather people, I knew that if I was desperate there must be other people. So I did a workshop 'lets talk about death'…I ran a couple of retreats…I organised a few walks because there was nothing in Dublin…" (Eileen Pugh, M50 Soulfriends)

Prof Kellehear highlighted that people commonly forget that they too will die someday. Therefore, what we do today to build compassionate communities will not only benefit other people but also ourselves. Keeping our own immortality in mind should serve as motivation to build compassionate communities. Alison Bunce, founder of Compassionate Inverclyde, reiterated that ordinary people make a difference together, and everyone has something to offer someone else. Compassionate communities start from a desire, that turns into a vision, and then to action. Developing compassionate communities initiatives is up to all of us.

"Theres no time like today and the phone is at the end of your hand" (Professor Allan Kellehear)

Compassionate communities can begin with simple actions, and impactful initiatives may not directly or conventionally focus on healthcare. During roundtable discussions, attendees suggested practical ideas for compassionate communities initiatives for our island. These included caring neighbourhood watch programs, befriending services, connecting existing men's and women's sheds (and other existing organisations) and creating support guides for grief and illness. These realistic steps provide a clear starting point for communities looking to foster compassion and support.

A roadmap is needed

It was clear that the conference attendees were grateful for the real-life examples of compassionate communities projects that were provided during the conference. Each compassionate communities initiative was different and during the panel discussion, conference attendees questioned what the structure of a compassionate community should look like - whether it is better to have one large, coordinated effort or to have smaller efforts spread throughout the community. Prof Kellehear noted that we must be wary of a compassionate community growing too large and instead of focusing on getting bigger, the focus should be on breeding – encourage smaller communities to start around you rather than enveloping every initiative under one banner.

Whatever the roadmap to developing a particular compassionate community looks like, it's okay to go off track. When developing compassionate communities, not everything will go according to plan, and that's okay.

"A lot of this stuff we can't pre-plan, we've got to be open to unanticipated consequences…let's be open to all of the benefits that could happen." (Dr Guy Peryer, St Chrisopher's Hospice)

Opportunities for development

Conference attendees expressed a desire for a 'roadmap' or DIY toolkit to developing compassionate communities initiatives. Although it wouldn't be appropriate to be prescriptive, in terms of respecting that each community is different, it is reasonable for us to provide inspiration and practical guidance to those across the island who have an interest in developing their own initiatives. The roundtable discussions highlighted the need for examples of successful initiatives, and we are able to look both across the island of Ireland and further afield for these.

In particular, there is significant learning to be shared from those individuals and organisations identified throughout this position paper, and many others besides, who have developed and delivered compassionate communities initiatives. They too are valuable community assets and it is important that we retain their knowledge and experience, and facilitate mentorship and partnership working where we can. We also have the international community to draw upon.

FINDING Engagement from civic society across the island of Ireland is needed, to embed policies and support around caregiving, dying, death and grief within all our key institutions.

In order to foster compassionate communities across the island of Ireland, it is essential that we support grass roots initiatives and services working in close partnership with communities. However, a key message throughout the conference was the need to balance this with higher level support and systemic change across civic society. Civic society needs to be engaged and engaged beyond the context of health and social care. This is absolutely critical if compassionate support is to be available to people affected by serious illness, in all aspects of their lives.

A social ecological approach

Prof Kellehear (Northumbria University) emphasised the importance of a social ecological approach to the development of compassionate communities. This involves recognising how interactions between individuals, communities, and their broader social environments influence care and support for those facing serious illness, dying, death or grief. It recognises that people are embedded in multiple layers of social contexts—familial, community, cultural, institutional—and that compassionate care requires engagement across these interconnected layers.

The Compassionate Civic Charter

Dr Peryer (St Christopher's Hospice) echoed this, emphasising how equipping communities to be compassionate requires a community focus supported by a broader sociological approach, which can be usefully guided by the Compassionate City Charter. This is where whole cities or towns develop policies across their sectors. The Compassionate City Charter, co-developed by Prof Allan Kellehear, proposes that a city council will develop and support 13 social changes to the city's key institutions and activities. This for example includes; establishing policies within schools for care, dying, death and grief, having dedicated groups for end-of-life care support within places of worship, and promoting compassionate communities programmes in local neighbourhoods. This charter has also been amended to a Compassionate Civic Charter, recognising more explicitly the need to support work across both rural and urban communities (e.g. across council areas).

"In the matter of social, psychological and spiritual, every social institution in our society can provide palliative care and should. The workplace, the schools, the arts community, the neighbourhoods, the local government, the football club, the golf club. Each and every one of these institutions should provide palliative care because each and every one of them provides health care" (Professor Allan Kellehear, Northumbria University)

Ultimately, the development of partnership working at multiple levels was stressed as essential. During a panel discussion, Alison Bunce (Compassionate Inverclyde) discussed the development of relationships with local councils as having been key to the success of Compassionate Inverclyde. The benefit from these relationships will trickle both up and down, with compassionate communities and compassionate cities sustaining each other. The message was that you can of course still start grass roots, but it serves to court the leadership.

Palliative care as a civic responsibility

Prof Kellehear described how the city charter can be used as a tool to guide and regulate systematic cooperation in policy development. These policies need to be implemented, allowing public health funding and resources to be utilised to start, nurture, and grow compassionate communities. Hospices, palliative care services, and the community need to be empowered to contact civic institutions and ask what their palliative care policies are. This civic policy development is an important approach when engaging the community in palliative care.

"Every civic institution in our society should have palliative care policy - what palliative care are they providing? And only when that happens can we talk about continuity and quality of palliative care. Continuity and quality of palliative care is not just a matter of switching from doctors to social workers, or social workers to occupational therapists, it's about handing the patient back into their community, and find out how the community is continuing that palliative care when that adult or child goes back to school, back to the retirement home, back to shopping, back to the neighbourhood, back to the workplace, and back to worship. That's continuity of care, and it's where in the end palliative care becomes everybody's business." (Professor Allan Kellehear, Northumbria University)

In the U.K examples of already existing compassionate cities are Plymouth, Sheffield and Birmingham. Compassionate cities and compassionate communities, as long as partnership with health and social care providers is present, can and should be run by anybody. To date across the island of Ireland, Derry-Londonderry is the only city to develop a Compassionate Cities Charter

Opportunities for development

There is significant opportunity for local government, government departments, councils and civic institutions, both North and South, to help lead the way in prioritising a compassionate approach to caregiving, dying, death and grief. The Compassionate Civic Charter provides

Marie Curie Schools Bereavement Programme

Over the last 2-3 years, Marie Curie has developed the Schools Bereavement Programme to strengthen grief education and bereavement support in schools.

The programme has four phases.

1. Teacher training on loss and bereavement
2. Developing and delivering a loss and bereavement module
3. Analysing attitudes to grief education
4. Promoting the module and grief education to be embedded into the school curriculum

The programme has been piloted to 374 teaching staff across 162 schools in Northern Ireland.

Teachers' ability and confidence to support pupils with bereavement improved by 52%.

This training then kickstarted changes to be made to school policies:

"... we were able to use a lot of what I had learned at the course ... So a new version of the policy is now in place." (Senior Teacher)

Not only did teachers and schools benefit, but also the pupils and their families, as the programme created a supportive environment for families to process their grief.

"I'm a teacher of over 30 years' experience. I went into the course thinking what can they really tell me that I haven't already experienced? But no, I left there with many more tools for my toolbox."

SENIOR TEACHER

a systematic approach to ensuring engagement from all sectors of society. After the conference, Public Health Palliative Care International published the Bern Declaration 2024, which similarly urges governments, city administrations and all civic organisations within communities and cities to commit to a number of key health promotion principles and actions for the end of life for ALL people. Engagement with such frameworks would ensure that all sectors of our society—from schools and workplaces to local governments—actively participate in supporting individuals experiencing caregiving, dying, death and grief.

During the conference roundtable discussions, conference attendees proposed several actionable steps which align to this key message. Suggestions included implementing the Compassionate Civic Charter through local councils, establishing recognition programs and awards for compassionate groups and individuals, and developing practical palliative care policies within our public institutions. Increased resourcing of existing initiatives was also mentioned, including a role for closer collaboration between Departments of Health, Education and Communities to support the expansion of programmes which have started in libraries and schools (see Compassionate School Communities report) and to look for other opportunities for partnership working.

FINDING Strategic leadership and investment is essential to foster compassionate communities across the island of Ireland.

At the conference there was acknowledgement that a compassionate communities approach needs to be a central component of future palliative and end-of-life care on the island of Ireland. The reference to developing a new public health approach to palliative and end-of-life care in the Northern Ireland Regional Palliative Care in Partnership Programme was highlighted within the conference, and just after the conference we saw explicit reference to compassionate communities within the new National Adult Palliative Care Policy in Ireland. Top-down support to resource these key policies, as mentioned by several of the speakers, is absolutely essential if we are to see compassionate communities integrated into care for those at end-of-life across our island.

Cross-border collaboration

Tánaiste Michael Martin, delivering the conference opening address, emphasised that North/South collaboration needs to be deepened where it makes eminent sense to do so, with healthcare being one such area. The Tánaiste emphasised the importance of opportunities such as the conference, for providing a

clearer understanding of the ways in which North/South cooperation can be further harnessed. He expressed a desire to see more proposals for cross border co-operation from health practitioners. The Tánaiste made a point of emphasising the strength of the hospice movement across the island, as well as the significant value of our family/unpaid caregivers.

Indeed, many of the compassionate communities initiatives discussed at the conference, and highlighted in the exemplar projects throughout this report, have an element of cross-border co-operation. For example, Sharon Williams (Compassionate Communities NI) acknowledged the importance of cross-border collaboration in her presentation and emphasised that there is significant opportunity to develop compassionate infrastructure while thinking in cross-border terms. Sharon mentioned that Compassionate Communities NI are collaborating with Cavan County Council and the Irish Hospice Foundation, on a project called the Art of Life (see below). This cross-border collaborative project aims to normalise conversations around dying, death and grief using arts-based activities to help people reflect on what is important to them, so they can plan for later years with agency and independence.

The need for strategic leadership

The need for strategic leadership to foster a compassionate communities approach across the island of Ireland was referenced within the conference presentations and roundtable discussions. The conference profiled a number of organisations (e.g. Compassionate Communities NI, Irish Hospice Foundation) who are each delivering larger programmes of work around compassionate communities. We do not however have an organisation with the resource needed to support a compassionate communities network across the island. In the roundtable discussions, the need to either identify or establish an organisation to provide strategic leadership and vision for compassionate communities across the island of Ireland was endorsed. This organisation needs an appropriate level of Government investment, so that they are able to deliver on the sustained and long-term change needed. Aligned to this, conference attendees referenced the need to support compassionate communities champions across different sectors.

Financial support directed to the community

It was mentioned on numerous occasions throughout the conference how individuals and organisations managed to start and sustain compassionate communities initiatives with no financial backing. Had there been money available some of these initiatives would have availed of it, but they weren't going to let the lack of budget hold them back. However, it leaves us with

The Art of Life

The Art of Life is a cross-border project which aims to normalise conversations around death and dying using creative approaches.

This project is led by 'Creative Cavan' who have collaborated with the Irish Hospice Foundation, Compassionate Communities, Cavan Age Friendly, South West Age Partnership, Healthy Ireland at your library, Libraries NI and Cavan Library Service.

The project will be delivered during 2024 and 2025 and 'creatives', care professionals and the wider public will work together to maximise reach and build a lasting legacy.

The 'creatives' (artists) will be trained to lead the project and deliver a range of events across Cavan, Fermanagh and Tyrone.

Several death positive libraries and reading lists have been developed and an art piece reflecting the project has been commissioned that will be donated to a meaningful location.

"My heart and chest felt really warm after this - I felt as if the block of ice, that has been around my heart for 20 years, had melted. The opportunity to talk about death and dying was brilliant! I honestly feel this project should be made available to more people and groups. It is so beneficial."

PARTICIPANT IN AN 'ART OF LIFE' PROJECT

the question: why is there no money to support these initiatives? Compassionate communities are referenced within key national policies North and South, yet it is unclear how the movement can expand and be sustained for long enough to impact public health, without being valued through financial investment.

During a panel discussion, a community group leader from Lurgan echoed the speakers' sentiments that fostering compassionate communities is largely about stepping up. They described their group as having received little to no funding, yet they remain hopeful about growing and delivering initiatives similar to Compassionate Inverclyde, as outlined by Alison Bunce. While their passion and dedication will undoubtedly drive their success, one can't help but wonder how much more impactful or innovative their efforts could be with even modest financial support. Such backing could provide the resources needed to establish and sustain meaningful initiatives within their community.

Dominic Campbell (Irish Hospice Foundation) highlighted the value of financial support, noting that over the last three years, the Irish Hospice Foundation's Arts and Cultural Engagement Programme has been offering microgrants and mentorship to help people address the specific needs of their communities around the realities of dying, death and grieving. At least 62 microgrants have been awarded, which has enabled the creation of diverse initiatives, such as a graphic novel on perinatal grief and a project by bikers exploring how to memorialise their community members. These projects have led to a groundswell of conversation around dying, death and grief- both within communities but also online through the digital legacy of these projects. This is a clear example of how even modest financial support can unlock creative potential, enabling projects that might otherwise never have materialised. In the roundtable discussions, general financial priorities focused on increased funding, including seed-funding to enable smaller projects which could be appropriately evaluated and expanded, as well as incentives to enhance the well-being of volunteer carers, such as carers' credit.

Opportunities for development

Delivering on a compassionate communities approach is essential to ensuring that caregiving, dying, death and grieving are supported with dignity and care across the island of Ireland. As the Tánaiste highlighted in his address, there is an ongoing need for political and financial investment in healthcare, and this is particularly the case when it comes to fostering the compassionate approach to end-of-life care that the people of this island deserve. Throughout the conference, successful compassionate community initiatives were showcased, often driven by small groups of dedicated individuals. However, we cannot and should not rely on compassion alone to sustain these efforts.

Many existing compassionate communities initiatives across the island face significant challenges with either a complete lack of or else short-term funding, which limits their sustainability and potential reach. If we are to develop a compassionate communities approach at scale across the island, we need investment to build the appropriate infrastructure and investment in our communities. We also need to recognise the substantial experience and knowledge held within individuals, groups and organisations who have developed and led compassionate communities initiatives, and the importance of ensuring we retain this. We are a small island, and there is considerable potential for cross-border collaboration, enabling the sharing of resources, expertise, and successful strategies.

CONCLUSION

Across the island of Ireland, there is a pressing need to transform our experiences of caregiving, dying, death and grieving. Communities are uniquely positioned to support people to live as well as possible, until the end-of-life. This position paper highlights how fostering compassionate communities can address the challenges we face as an island which are associated with serious illness, while also aligning with key policy developments. Fully realising the vision of a compassionate approach to serious illness requires dedicated top-down support – both to ensure the right environment to support meaningful community development and also to achieve the systems level change needed to embed compassion across all sectors of society.

Empowering communities to lead in supporting those affected by serious illness, with the support of our valued specialist and generalist palliative care services and wider civic society, is vital for ensuring quality, continuity, and equity in care. To balance these care elements, there is an urgent need to increase community capacity around caregiving, dying, death, and grieving, and to drive broader systemic change across civic institutions. A strengths-based approach, which builds on existing compassion within communities across the island, will amplify the voices of those with lived experience, fostering a deeper understanding of place-based needs. Alongside this, the development of compassionate civic charters is essential to both support community efforts and to ensure that individuals affected by serious illness encounter compassion in every aspect of their lives.

A social ecological approach, as emphasised by Prof. Kellehear, underscores the need to nurture compassion at every societal level, from families to institutions, ensuring caregiving, dying, death, and grieving are seen as collective responsibilities. Cross-border partnerships offer further potential, allowing resources and expertise to be shared for the benefit of communities across the island. By uniting community-driven action with robust support from wider civic society, the island of Ireland can cultivate a compassionate culture that transforms care for those facing serious illness, death, and end-of-life challenges.

Recommendations

These recommendations are informed by the key findings of this position paper and have been refined through workshops with key stakeholders. They are grounded in the principle that people with lived experience and communities themselves must be at the heart of delivering on each recommendation. It is essential that communities are engaged as active partners—not only as recipients but as co-creators who shape, implement, and sustain these initiatives. Their insights, needs, and strengths should guide every phase, ensuring that each action is relevant, empowering, and responsive to local contexts.

Caregiving, dying, death and grieving should not be the responsibility of health and society care. As such, it is our position that to deliver on the following recommendations, a clear mandate for fostering compassionate communities is needed from local government both North and South, with the recommendations translated into specific actions and delivered through relevant government departments.

Recommendations

1 Advocate for the adoption and implementation of this paper's recommendations by engaging with local government, government departments, councils and civic leaders

Achieving meaningful change in how we experience caregiving, dying, death and grief across the island of Ireland requires committed, top-down support. There is a need for collective action to lobby local government, government departments, councils and civic leaders, to ensure they understand the need for compassionate communities and agree to adopt and deliver on the recommendations in this report to ensure the people of this island receive integrated compassionate care in all aspects of their life and death. There is alignment between compassionate communities and key policies within health and social care. However, it is essential to recognise that developing a compassionate approach to caregiving, dying, death and grief should be a shared responsibility across all government departments, councils and civic institutions. As such, fostering a compassionate communities approach should be mandated for at a local government level.

2 Support/establish an organisation with secured funding for at least five years to provide strategic leadership and act as a knowledge broker for compassionate communities across the island of Ireland

There is need to support an existing organisation, or establish a new organisation, to provide strategic leadership to foster compassionate communities across the island of Ireland. This would include hosting a network, in order to support partnership working, knowledge exchange and awareness raising activities. This would necessitate longer-term investment and appropriate staffing, which would enable the organisation to take the lead on delivery of the subsequent recommendations, in partnership with other key organisations, and with the community at its centre. The organisation could be funded through cross-border investment, enhancing the vision of the Shared Island Initiative, where all communities across the island of Ireland work together towards a shared (and more compassionate) future.

3 Deliver public awareness campaigns around the concept and benefits of compassionate communities, linked to providing recognition and reward to existing initiatives

To help mobilise community action, there is need to increase social awareness across the island of Ireland about both the concept and benefits of compassionate communities initiatives. This should be linked to providing recognition and reward to existing initiatives. Such public awareness raising activity could be embedded within existing campaigns to raise awareness and understanding of palliative care; a recommendation within the new National Adult Palliative Care Policy (2024) in Ireland and delivered within the Regional Palliative Care in Partnership Programme in Northern Ireland.

4 Commission and complete an asset-mapping exercise to identify compassionate communities initiatives and community groups with potential to deliver initiatives across the island of Ireland. The results should be published in a publicly accessible online map and updated every six months

A comprehensive understanding of initiatives being delivered which align to a compassionate communities approach is required, alongside identifying existing community groups who could be supported - with additional capacity building activity - to deliver such initiatives. Asset-mapping needs to be preceded by public awareness raising activities *(see Recommendation 3)*, in acknowledging that individuals and community groups may not easily identify with the compassionate communities movement.

5 Facilitate engagement workshops in communities across the island of Ireland, to identify local need and establish partnership working between communities and health and social care

Creating regular opportunities to amplify the voices of those who have lived experience of caregiving, death, dying and grieving is vital. Consideration of equality and diversity should be at the forefront when planning, to ensure the full diversity of voices from across our island can be heard Engagement workshops will foster relationships and ultimately build trust with the community, including both individuals and community groups existing there (linked to Recommendation 4). The engagement workshops are a key opportunity to promote access to seed funding and mentorship (Recommendation 6). The importance of establishing the community as an equal partner in care has long been highlighted in North/South policy. Only by engaging with communities will it be possible to create specific priorities and identify action which will have meaningful results for that specific community and in alignment with their unique culture.

Recommendations

6 Provide seed funding and mentorship for community groups to work in partnership with health and social care, to develop, deliver and evaluate impact of localised compassionate communities initiatives

It is essential that mentorship and funding are easily accessible to individuals and community groups, to develop and implement initiatives based on their lived experience and in response to community need, and in partnership where appropriate with health and care services. A considered approach to the advertisement, application process and decision-making around allocation of support is needed. There is need to remove barriers for grass-roots initiatives to apply for funding. Overall, funding eligibility should be contingent on demonstration of close partnership working with community members. Appropriate funding and mentorship are needed to facilitate robust evaluation of impact, which may then maximise knowledge transfer by helping us to understanding which approaches work for whom, and in which circumstances. In the Republic of Ireland, this funding and mentorship could be facilitated through competitive applications to the Sláintecare Healthy Communities Programme, as referenced in the new National Adult Palliative Care Policy (2024).

7 Support the development of compassionate communities of practice, to share and to mobilise learning from existing compassionate communities initiatives

There is a need to retain and mobilise the lessons learned from existing compassionate communities initiatives. Through establishing compassionate communities of practice which are placed-based or aligned to specific populations or needs, opportunities for collective learning, networking and problem-solving will help to refine work that is already going on, sustain initiatives, and inspire future work. This will also be necessary to support collaborative engagement across the island of Ireland.

8 Establish steering groups for the development and delivery of compassionate civic charters in council areas both North/South

There is a need to promote civic policies and practices for supportive care inside all civic sectors- from workplaces, schools, or faith groups to social clubs, cultural centres and neighbourhoods. The establishment of steering groups- led by local councils in partnership with leaders from across civic society and community members- should develop and deliver on tailored compassionate civic charters reflecting the needs of their locality. Government departments should also look for opportunities to work together on a regional basis to deliver larger programmes of work, for example delivering on the recommendations within the 'Compassionate School Communities' report and initiating similar work in other key sectors. Developing and delivering on a compassionate civic charter will ensure the systems level change needed across all sectors of society.

9 Commission research to support a 'roadmap' for fostering compassionate communities across the island of Ireland, focused on understanding local need, understanding what has worked for whom, where, and in what circumstances, and embedding best practice

There is a need to ensure the development of compassionate communities across the island of Ireland is informed by a robust evidence base of community-engaged research. Research supporting compassionate communities will allow for a more thorough understanding of the development, impact and sustainability of initiatives within our context, and will help ensure learning both regionally and internationally is reflected in practice.

REFERENCES

References

1. May P, Johnston BM, Normand C, Higginson IJ, Kenny RA, Ryan K. Population-based palliative care planning in Ireland: how many people will live and die with serious illness to 2046?. HRB open research. 2020 Jan 28;2:35.
2. McKeaveney C, McConnell T, Harrison C, Stone V, Reid J. Population-based projections of place of death for Northern Ireland by 2040. Palliative Medicine and Hospice Care. 2020 Dec 30;6(2):22-33.
3. Saunders DC. Cicely Saunders: selected writings 1958-2004. Oxford University Press; 2006 Jan 5.
4. Kellehear A. The social nature of dying and the social model of health. Oxford textbook of public health palliative care. 2022 Mar 31:22-9.
5. Abel J, Kellehear A. Palliative care reimagined: a needed shift. BMJ Support Palliat Care 2016;6:21-6
6. D'Eer L, Sallnow L. Compassionate Communities: contemporary tensions and challenges. Annals of palliative medicine. 2024 Jan 31;13(1):5-9.
7. Patel M, Noonan K. Community development. Oxford Textbook of Public Health Palliative Care. 2022 Mar 31:107.
8. Mills J, Abel J, Kellehear A, Noonan K, Bollig G, Grindod A, Hamzah E, Haberecht J. The role and contribution of compassionate communities. The Lancet. 2023 Oct 13.
9. McLoughlin K. Compassionate Communities Project Evaluation Report. 2013 Sept 30.
10. Vanderstichelen S, Dury S, De Gieter S, Van Droogenbroeck F, De Moortel D, Van Hove L, Rodeyns J, Aernouts N, Bakelants H, Cohen J, Chambaere K. Researching Compassionate Communities from an interdisciplinary perspective: the case of the Compassionate Communities Center of Expertise. The Gerontologist. 2022 Dec 1;62(10):1392-401.
11. Librada-Flores S, Nabal-Vicuña M, Forero-Vega D, Muñoz-Mayorga I, Guerra-Martín MD. Implementation models of compassionate communities and compassionate cities at the end of life: a systematic review. International journal of environmental research and public health. 2020 Sep;17(17):6271.
12. Sallnow L, Paul S. Understanding community engagement in end-of-life care: developing conceptual clarity. Critical Public Health. 2015 Mar 15;25(2):231-8.
13. Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. QJM: An International Journal of Medicine. 2013 Dec 1;106(12):1071-5.
14. Abel J, Kellehear A, Karapliagou A. Palliative care — the new essentials. Ann Palliat Med. 2018;7(Suppl 2):S3–S14.
15. Kellehear A. *The Compassionate City Charter*. https://compassionate-communitiesuk.com/wp-content/uploads/2021/12/The-Compassionate-City-Charter.pdf [accessed 22nd October 2024].
16. Roleston C, Shaw R, West K. Compassionate communities interventions: a scoping review. Annals of palliative medicine. 2023 Jul 17.
17. Sallnow L, Smith R, Ahmedzai SH, Bhadelia A, Chamberlain C, Cong Y, Doble B, Dullie L, Durie R, Finkelstein EA, Guglani S. Report of the Lancet Commission on the Value of Death: bringing death back into life. The Lancet. 2022 Feb 26;399(10327):837-84.
18. Hartley N. 'Let's Talk About Dying': Changing Attitudes Towards Hospices and the End of Life. InInternational perspectives on public health and palliative care 2013 Jul 3 (pp. 156-171). Routledge.
19. Abel J, Bowra J, Walter T, Howarth G. Compassionate community networks: supporting home dying. BMJ Supportive & Palliative Care. 2011 Sep 1;1(2):129-33.
20. Cronin P. Compassionate communities in Shropshire. *The Irish Hospice Foundation. Abstracts of the 3rd International Public Health & Palliative Care Conference 2013,. Limerick, Ireland: Milford Care Centre, University of Limerick*. Ireland: 2013:43
21. Office for National Statistics (ONS), statistical bulletin, [released 30 January 2024] *National population projections: 2021-based interim* https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2021basedinterim [Accessed 22nd Oct 2024].

22. Central Statistics Office, press statement, [released on Older Persons Information Hub January 2024] *CSO Older Persons Information Hub Provides a Snapshot of the Lives of Older People in Ireland.* https://www.cso.ie/en/csolatestnews/pressreleases/2024pressreleases/pressstatementolderpersonsinformationhub2024/#:~:text=CSO%20Older%20Persons%20Information%20Hub,to%201.6%20million%20by%202051. [Accessed 22nd Oct 2024]
23. NISRA., statistical bulletin, [released 2021 April 19] *2018-based Population Projections for Northern Ireland* https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/NPP18_Bulletin.pdf [Accessed 22nd Oct 2024].
24. AIIHPC, *Almost 70% say they don't mind where they receive palliative care as long as they have a good quality of life (NI)* https://aiihpc.org/almost-70-say-they-dont-mind-where-they-receive-palliative-care-as-long-as-they-have-a-good-quality-of-life-ni/ [Accessed 22nd Oct 2024].
25. McKeown K, Irish Hospice Foundation. Enabling more people to die at home: making the case for quality indicators as drivers for change on place of care and place of death in Ireland. Irish Hospice Foundation; 2014 Dec 4.
26. Damery M, Forster N, Mackay E. *Dying well at home focus group report*, Irish Hospice Foundation, 2023 https://hospicefoundation.ie/wp-content/uploads/2023/09/Dying-Well-at-Home-Report-Irish-Hospice-Foundation.pdf [Accessed 22nd Oct 2024].
27. Murray E. *Access to Specialist Palliative Care Services and Place of Death in Ireland. What the data tells us.* McLoughlin K, Foley S (eds.) Irish Hospice Foundation, 2013. https://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf [Accessed 22nd Oct 2024].
28. Department of Agriculture, Environment and Rural Affairs. *Rural policy framework for NI.* 2022 https://www.daera-ni.gov.uk/sites/default/files/publications/daera/Rural%20Policy%20Framework%20for%20NI%20-%20Full%20Version%20%28March%202022%29.PDF [Accessed 22nd Oct 2024].
29. Government of Ireland. *Our rural future: Rural development policy 2021-2025.* 2021 https://www.gov.ie/pdf/?file=https://assets.gov.ie/132413/433aebac-f12a-4640-8cac-9faf52e5ea1f.pdf#page=22 [Accessed 22nd Oct 2024].
30. DoHC. Palliative care for children with life limiting conditions in Ireland - a national policy. In: ROI DoHaC, editor. 2009.
31. NI Children's Hospice. NI Children's Hospice 2024 https://www.nihospice.org/our-services/children-s-services/. [Accessed 11th Nov, 2024]
32. Hughes Z, Alliance C. Rural carers in Ireland: Challenges & opportunities. Care Alliance Ireland Discussion Paper Series. 2018.
33. Teahan Á, Lafferty A, Cullinan J, Fealy G, O'Shea E. An analysis of carer burden among family carers of people with and without dementia in Ireland. International Psychogeriatrics. 2021 Apr;33(4):347-58.
34. Central Statistics Office. *Census 2022 profile 4 - Disability, health and carers.* 2023, September 28 https://www.cso.ie/en/releasesandpublications/ep/p-cpp4/census2022profile4-disabilityhealthandcarers/carers/ [Accessed 22nd Oct 2024].
35. McConnell T, Finucane A, Hanna J, Harrison C, Hudson B, McCullagh A, Paradine S, Patynowska K, Reid J. *Experiences of loneliness among people at the end of life and their carers in Northern Ireland.* Marie Curie. 2022. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/experiences-of-loneliness-among-people-at-the-end-of-life-and-their-carers-in-northern-ireland.pdf [Accessed 22nd Oct 2024].
36. Aoun SM, Richmond R, Gunton K, Noonan K, Abel J, Rumbold B. The Compassionate Communities Connectors model for end-of-life care: implementation and evaluation. Palliative Care and Social Practice. 2022 Nov;16:26323524221139655.
37. Aoun SM, Rosenberg J, Richmond R, Rumbold B. The Compassionate Communities Connectors programme: experiences of supported families and referring healthcare providers. Palliative Care and Social Practice. 2023 May;17:26323524231173705.
38. Graham-Wisener L, Dempster M, Sadler A, McCann L, McCorry NK. Validation of the Distress Thermometer in patients with advanced cancer receiving specialist palliative care in a hospice setting. Palliative Medicine. 2021 Jan;35(1):120-9.
39. McGarrigle CA, Ward M, De Looze C, O'Halloran A, Kenny RA. Caring in the time of COVID-19, longitudinal trends in well-being and mental health in carers in Ireland: Evidence from the Irish Longitudinal Study on Ageing (TILDA). Archives of gerontology and geriatrics. 2022 Sep 1;102:104719.
40. Moriarty J, Maguire A, O'Reilly D, McCann M. Bereavement after informal caregiving: assessing mental health burden using linked population data. American journal of public health. 2015 Aug;105(8):1630-7.

41. Irish Hospice Foundation. Adult Bereavement Care Pyramid. 2020. https://hospicefoundation.ie/our-supports-services/bereavement-loss-hub/i-work-in-bereavement/adult-bereavement-care-pyramid/ [Accessed 22nd Oct 2024]
42. Harrison C, Graham-Wisener L, McEwan J, Nelson A, Berry E, Dempster M, Shayegh J, Bryne A, Islam I. Creating a Death Literate Society: The importance of boosting understanding and awareness of death, dying and bereavement in Northern Ireland.
43. Marie Curie. Creating a Death Literate Society [Internet]. 2022 [Internet]. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/creating-a-death-literate-society.pdf [Accessed 11th Nov, 2024]
44. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, Matlock DD, Rietjens JA, Korfage IJ, Ritchie CS, Kutner JS. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. Journal of pain and symptom management. 2017 May 1;53(5):821-32.
45. Brinkman-Stoppelenburg A, Rietjens JA, Van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. Palliative medicine. 2014 Sep;28(8):1000-25.
46. Solinís RN, Hasson N, Idoiaga GE, Molina EH, Flores SL, Rodriguez C. Impact of a home-based social program in end of life care in the Basque Country: SAIATU Program. International Journal of Integrated Care (IJIC). 2014 Oct 2;14.
47. Abel J, Kingston H, Scally A, Hartnoll J, Hannam G, Thomson-Moore A, Kellehear A. Reducing emergency hospital admissions: a population health complex intervention of an enhanced model of primary care and compassionate communities. British Journal of General Practice. 2018 Nov 1;68(676):e803-10.
48. Aoun SM, Bear N, Rumbold B. The compassionate communities connectors program: effect on healthcare usage. Palliative Care and Social Practice. 2023 Oct;17:26323524231205323.
49. Lolich L, Lynch K. No choice without care: palliative care as a relational matter, the case of Ireland. Soundings: An Interdisciplinary Journal. 2017 Nov 1;100(4):353-74.
50. AIIHPC. Briefing Paper: Public health approaches to palliative care. 2017. https://aiihpc.org/wp-content/uploads/2015/02/Briefing-Paper-Public-Health-Approaches-to-Palliative-Care-Nov-2017.pdf. [Accessed 23rd Oct 2024]
51. Irish Hospice Foundation. The Public Health Approach to Dying, Death and Bereavement: An Irish Hospice Foundation Discussion Paper. 2019. https://www.lenus.ie/bitstream/handle/10147/628937/IHF-Public-Health-Report-to-dying-death-and-bereavement-2019.pdf?sequence=1&isAllowed=y. [Accessed 23rd Oct 2024]
52. AIIHPC & IHF. Round Table on a Public Health Approach to Palliative and End of Life Care on the island of Ireland. 2019. https://aiihpc.org/wp-content/uploads/2020/06/Round-Table-Report.pdf. [Accessed 23rd Oct 2024]
53. Dumont K, Marcoux I, Warren É, Alem F, Alvar B, Ballu G, Bostock A, Cohen SR, Daneault S, Dubé V, Houle J. How compassionate communities are implemented and evaluated in practice: a scoping review. BMC Palliative Care. 2022 Jul 20;21(1):131.
54. Ganz M. *Why stories matter*. Sojourners. 2009:38(3), 16. https://commonslibrary.org/wp-content/uploads/Why-Stories-Matter_-Marshall-Ganz.pdf [Accessed 23rd Oct 2024].

QUEEN'S UNIVERSITY BELFAST

Compassionate Communities: Position Paper Fostering Compassionate Communities: A Call To Transform Caregiving, Dying, Death And Grieving On The Island Of Ireland

AIIHPC
The All Ireland Institute of Hospice and Palliative Care

Irish Hospice Foundation

Foyle Hospice
Together we care

HSC Public Health Agency

An Roinn Gnóthaí Eachtracha
Department of Foreign Affairs

Marie Curie

Care and support through terminal illness

Creating a death literate society

The importance of boosting understanding and awareness of death, dying and bereavement in Northern Ireland

Cardiff University / Prifysgol Caerdydd

Canolfan PRIME Cymru / PRIME Centre Wales

Queen's University Belfast

Contents

Introduction

With an aging population and growing palliative care needs, more and more people in Northern Ireland are being impacted by death, dying and bereavement with each passing year.

For understandable reasons, many people here don't like to think about death and would rather put any talk of it on the long finger until it can no longer be avoided. But what impact does this have?

How are our end of life and bereavement experiences affected if we have little awareness or knowledge of the practical matters of death and dying? What happens when someone close to us is diagnosed with a terminal health condition and we don't know very much about the care they need and how it is accessed? What are the consequences for the care we receive when we're dying if we haven't ever discussed our end of life wishes with our loved ones or clinicians? **Put another way, what are the impacts of 'death illiteracy'?**

Death literacy concerns the knowledge, skills and awareness of issues concerning death, dying, end of life care and bereavement. It is about understanding these issues and having the ability to put that knowledge into practice – not only for own benefit, but to support those within the wider community who are impacted by death and dying as well.

Death literacy is, perhaps, an unfamiliar concept in Northern Ireland, but a crucial one that will significantly impact the end of life and bereavement experiences of every person who lives and dies here. This report examines the importance and impact of death literacy and – based on new survey data – provides a snapshot assessment of levels of death literacy in Northern Ireland.

It shows that there are important gaps in death literacy among the local population, with too many people unprepared for the end of life and unaware of where and when they can access support when they're impacted by death, dying and bereavement.

Finally, the report provides recommendations that we believe can help address Northern Ireland's death literacy problem in the months and years ahead.

Death literacy is a growing area of study and scholarship around the world, but there is a lack of robust evidence that is specific to Northern Ireland. Given the enormous impact that death illiteracy can have, this situation needs to be addressed. We hope this report can play a small role in bridging that evidence gap, and maybe even spark a renewed interest in the subject among local policymakers and health and social care leaders.

Methodology

This report is based primarily on a survey of public attitudes to death and dying in Northern Ireland, carried out in 2021 and designed by a research partnership of Marie Curie; the School of Psychology, Queen's University Belfast; and the Marie Curie Palliative Care Research Centre and Division of Population Medicine, Cardiff University.

The survey was completed by 506 adults in Northern Ireland. The same survey was also conducted in England, Scotland and Wales, offering the opportunity to compare findings across these jurisdictions.[1]

Context

What is death literacy and why is it important?

Death literacy is commonly described as a set of knowledge and skills that make it possible to gain access to, understand and make informed choices about end of life and death care options. Populations with high levels of death literacy will have context-specific knowledge about the 'death system' where they live and the ability to put that knowledge into practice [2] [3] – both for their own benefit and to support those within the wider community who are impacted by death and dying.

'Death systems' are defined as the means by which death and dying are understood, regulated and managed in a society. They include and involve several components – including **people** (e.g. health and social care practitioners, funeral workers, religious leaders), **places** (e.g. hospitals, hospices, mortuaries, cemeteries), **times** (e.g. death anniversaries and remembrance days), **symbols and rituals** (e.g. last prayers) and more. [4]

Much like health literacy is about a person's ability to understand and use information to make decisions about their health, [5] death literacy enables people to engage, in an informed way, with issues of death, dying and bereavement.

When this death-related knowledge and awareness is delivered and facilitated through the community and other actors such as schools, workplaces, churches and more, this can be understood as a public health or health promotion approach – helping to change attitudes, behaviours and experiences of death, dying and bereavement in different populations. [6] [7] (see pages 11 and 14).

Researchers define a number of specific features or components that characterise death literacy. While they are grouped in other ways elsewhere, in this report, we combine them under the themes of *death knowledge and death skills.*

Death knowledge

This component of death literacy includes factual knowledge and understanding of the death system and the dying process, including what palliative and end of life care involves and who provides it. For example, a person with high levels of death literacy may be familiar with key palliative and end of life care terms/phrases and know how these services are accessed by patients and their loved ones.

Death knowledge also covers knowledge of end of life planning processes (e.g. advance care plans, wills, funerals etc.); what could be called 'death administration' – for example, how a death certificate is obtained; and community-level knowledge, such as awareness of the sources of support available for groups like end of life carers and bereaved people in the places they live.

Death skills

Death skills refers to the confidence and ability to talk about death, dying, and bereavement with others. This may include conversations with family, friends or health and social care professionals about issues like end of life wishes and planning, and experiences of loss and grief. [8]

Though there is some degree of overlap between elements of *death knowledge* and *death skills*, increased levels of knowledge can increase the confidence and ability to discuss issues of death and dying.

Why does death literacy matter?

While it may be a relatively unheard-of concept among the general population in Northern Ireland, death literacy is incredibly important.

Knowledge and understanding of palliative care impacts on access to quality care for dying people. [9] Robust knowledge of these services, and the range of other supports available, is therefore key to ensuring households and families impacted by terminal illnesses are able to access care and support when and where they need it.

Even in the best of circumstances, navigating Northern Ireland's complex Health and Social Care system is difficult – this difficulty will only be compounded if people at the end of life are unable to make informed decisions based on a strong understanding of the available services and how they're accessed.

When we acquire *death knowledge* and skills, it allows a whole-community approach to supporting those who are experiencing death, dying and bereavement.

This may help to take some of the burden off end of life carers – many of whom face exhaustion, burnout and declining health and wellbeing as a result of their caring role.[10]

In death literate communities, people can talk openly about death and dying. This helps to increase engagement with palliative care services [11] and also leads people to feel more capable of sharing their end of life wishes. Such agency around a person's end of life wishes is a benefit in its own right and reduces the distress facing their loved ones, who would otherwise be left to make decisions on their behalf. [12] It can also avert potential conflict between different health professionals, family members and care agencies. [13]

Failure to have these conversations during the routine days of living results in decisions being made in times of declining health or crisis, affecting the quality and range of care and support available to patients and their loved ones; and impacting on people's ability to die where or how they would wish. [6]

Layton Thompson/Marie Curie

The Department of Health's Advance Care Planning Policy document reinforces these ideas, highlighting the wide range of benefits when people have meaningful conversations about end of life wishes, including: an enhanced quality of life; peace of mind, giving people the opportunity to put their affairs in order; easing caregiver concerns and clarifying a person's wishes at the end of life for those closest to them. [14]

While there are many factors and interventions necessary to encourage end of life discussions and advance care planning, high levels of death literacy are a crucial facilitator/driver.

In the bereavement phase, good levels of death literacy are also critical to ensuring newly bereaved people can identify their grief and seek out relevant information and support to help them manage it. As a consequence, they may avoid some of the complications sometimes associated with the grieving process, such as depression and wider mental ill-health. [15] In this sense, death literacy can help increase collective wellbeing and resilience among bereaved people.[8] Understanding the death process and knowing what to expect may also ease bereavement experiences.

The issue of death literacy among children and young people is strongly debated, even though experiencing death is an inescapable reality for many of them. Up to date statistics are hard to find, but it is estimated that around 1,500 children under the age of 18 in Northern Ireland were bereaved of a parent in 2015, [16] and this figure doesn't cover the many more who are bereaved of siblings, grandparents and other loved ones each year.

Evidence suggests that some children have a desire for access to information and education about death and recognise the importance of this – including in helping them to prepare for the experience of personal bereavement. [17]

In a VotesForSchools poll, run in collaboration with the UK Commission on Bereavement in 2022, 58% of 7-11 year old students across the UK, and 38% of 12-16 year old students, said that coping with loss and bereavement should be taught at school. [18]

Despite this, many children and young people do not have the opportunity to talk or learn about death and dying, whether that is in school or other settings. Researchers argue that this may be doing them harm – fostering confusion and ignorance about death, [13] stifling understanding of grief and the natural responses to it, and even creating obstacles to receiving meaningful bereavement support when they experience the loss of a loved one. [19]

Knowledge and understanding of the issues associated with death, dying and bereavement has the potential to significantly shape end of life experiences for everyone in Northern Ireland. The next chapter of this report analyses new survey data to provide a snapshot of death literacy levels among the local population.

Philip Hardman/Marie Curie

Levels of death literacy in Northern Ireland

Our survey on public attitudes to death and dying in Northern Ireland offers unique insights into levels of death literacy among the local population. With the same survey having been carried out in England, Scotland and Wales, we are also able to compare local levels of death literacy with those across the UK, helping to identify both strengths and areas for improvement in Northern Ireland.

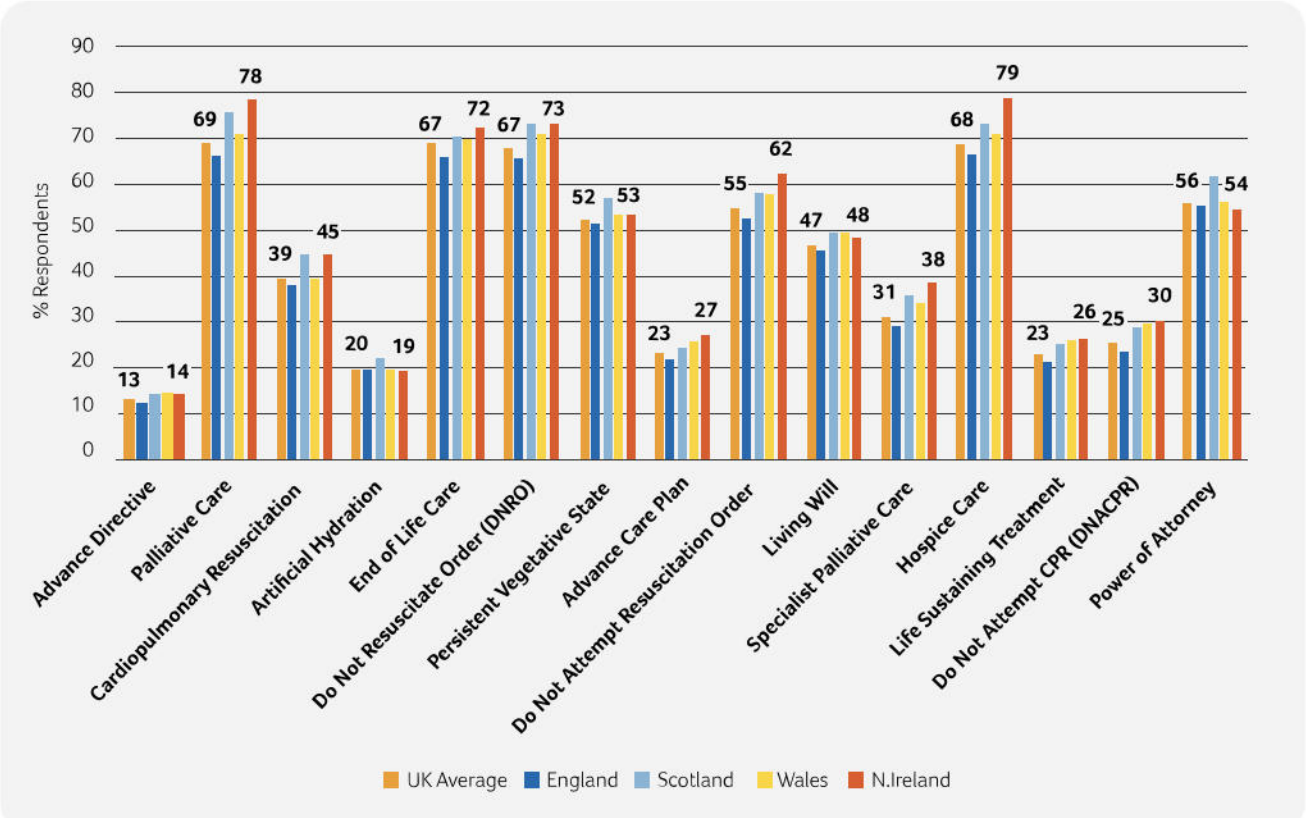
This chapter is divided into three primary sections, examining: i) Familiarity with key palliative and end of life care terms; ii) Talking to others about death, dying and bereavement; and iii) Finding support and information in the context of death, dying and bereavement.

Familiarity with key palliative and end of life care terms

Awareness and understanding of the core elements of palliative and end of life care is central to the knowledge element of death literacy. Our survey presented a number of relevant terms and asked respondents if they were familiar with them.

As Chart 1 illustrates, respondents in Northern Ireland performed favourably compared to their peers across the UK – with higher familiarity with 13 out of the 15 terms in NI compared to the UK average. Across the four individual jurisdictions, respondents in Northern Ireland had the same or higher levels of familiarity with 11 out of the 15 terms.

Chart 1 Which palliative and end of life care terms are you familiar with?



That being said, the local results are still cause for concern. Less than 50% of people in Northern Ireland were familiar with over half (8 out of 15) of the terms – and in some cases, recognition was even lower still.

Less familiarity with specialist terms like 'artificial hydration' and 'life sustaining treatment' was to be expected, but more than one in five people were not familiar even with more common terminology like 'palliative', 'end of life' and 'hospice care'. Given that these services make up core parts of the care and support that people will need when living with terminal illnesses, the lack of awareness of them among such large proportions of the public is very worrying.

The results for advance care planning (ACP) were even worse, with 73% of people unfamiliar with that term, and low levels of recognition of some of the documentation and processes involved. For example, 86% were unfamiliar with 'advance directive', over half (52%) were unfamiliar with 'living will' and 46% were unfamiliar with 'power of attorney'. People in Northern Ireland were less familiar with these latter two terms than their peers in Scotland and Wales by a range of 1-7%.

The impact of this is, arguably, illustrated when we asked people whether they had undertaken any activity in relation to advance care planning (Chart 2). Only a minority reported having done so, while a sizeable group responded negatively to the idea of ever engaging with the process in the future. This included 22% who said they would not, or did not intend, to speak to a doctor or nurse about their end of life wishes.

We may reasonably conclude that these trends are explained, at least partially, by a lack of awareness of advance care planning and its benefits – fundamentally an issue of death literacy (other contributing causes linked to death literacy are discussed in the next sections).

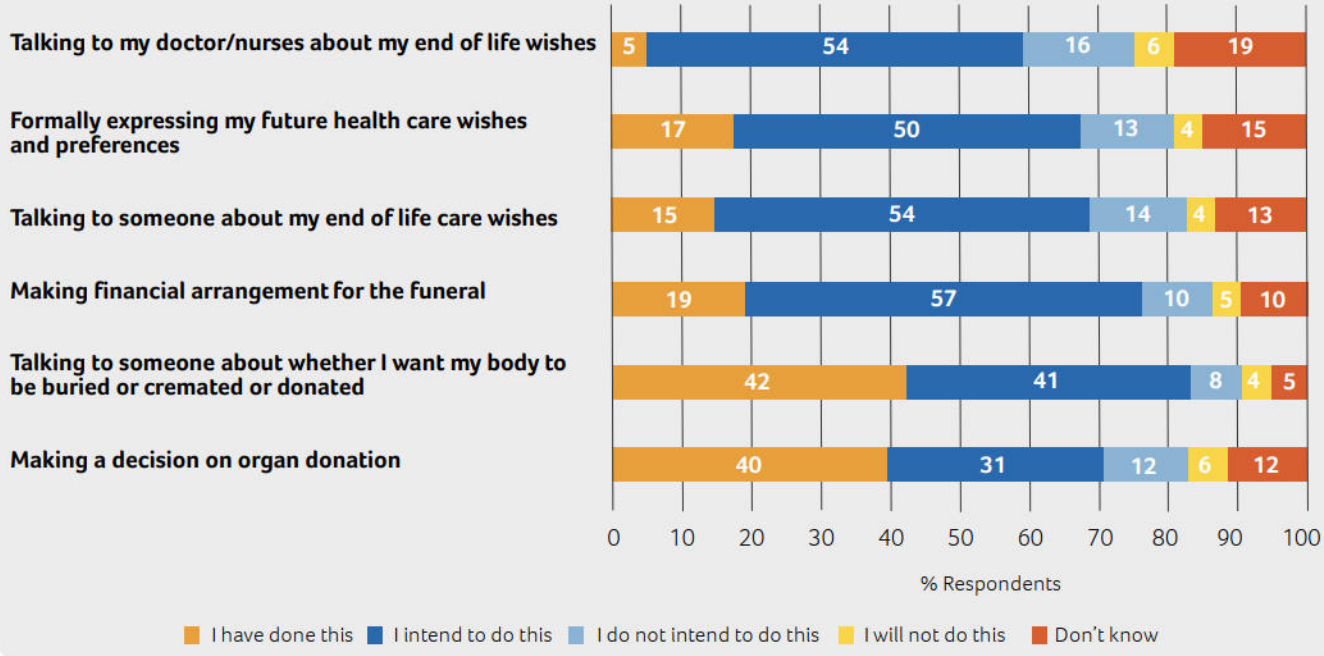
1 in 5

people in Northern Ireland were unfamiliar with the terms 'palliative care', 'end of life care' and 'hospice care'.

73%

of people in Northern Ireland were unfamiliar with the term 'advance care planning'.

Chart 2 Select an option to express your position on the following statements



Finally, it is worth highlighting the low levels of familiarity with terms related to resuscitation. More than one in four people in our survey were unfamiliar with the term 'Do Not Resuscitate Order' (DNRO), nearly 40% were unfamiliar with 'Do Not Attempt Resuscitation' (DNAR), and less than a third were familiar with 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR).

Decisions about resuscitation may be among the most important any of us can make about the way we would like to die. They help to prevent inappropriate interventions at the end of life – ensuring the person's last hours or days are spent as peacefully as possible [20] and avoiding added distress to families and loved ones. Raising greater awareness of these vital components of end of life planning ought to be a priority for health and social care stakeholders.

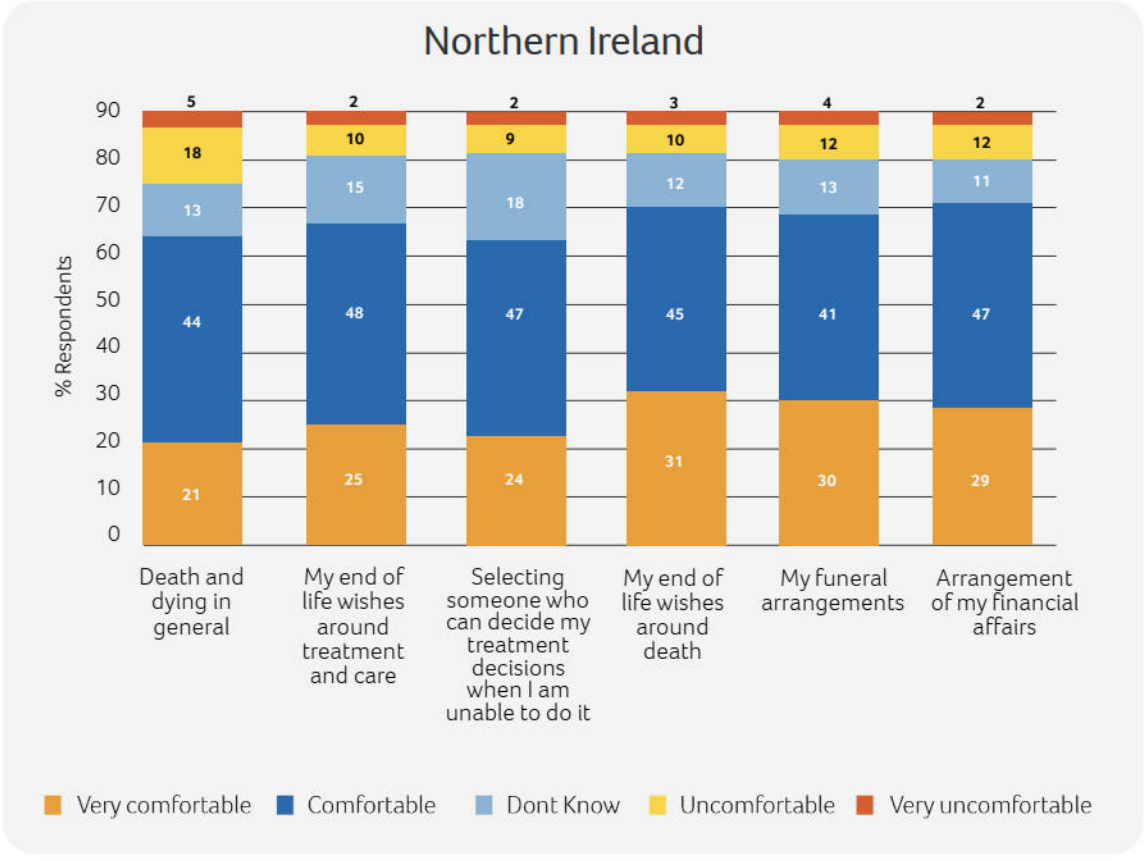
Talking to others about death, dying and bereavement

As highlighted in page 4, the willingness and ability to talk openly about matters of death, dying and bereavement is one of the central skills of a death literate population. When we asked how much Northern Ireland, as a society, talks about death and dying, 11% answered 'too much' – the highest proportion in the UK (3% more than in Wales, 2% more than in England and 8% more than in Scotland).

Our survey also specifically examined people's willingness to talk about these issues with two groups – their friends and family and their doctors and nurses.

Nearly two-thirds (65%) of people said they were comfortable/very comfortable talking to their friends and family about death and dying in general, with 73% saying the same about their end of life treatment and care wishes. Slightly more (76%) said they were comfortable/very comfortable talking about their end of life wishes around death (Chart 3).

Chart 3 How comfortable would you feel discussing the following topics with your family and friends?



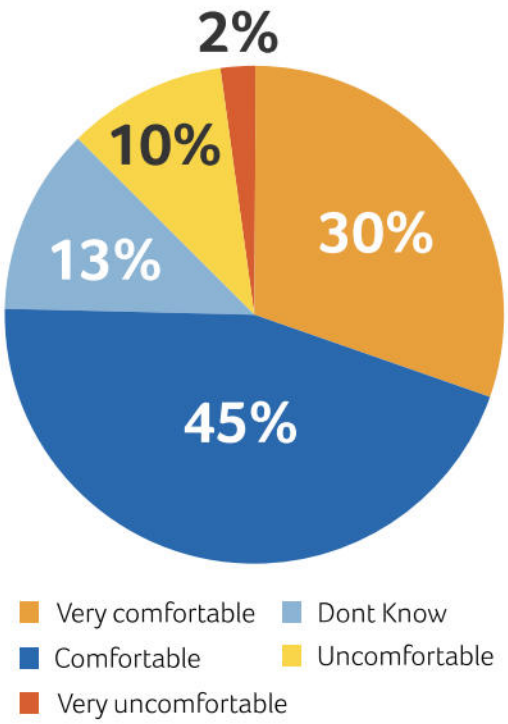
These trends are welcomed, but when we analyse the number of negative responses to these questions, it casts the results in a more worrying light.

In Northern Ireland, nearly one in four people (23%) said they were uncomfortable/very uncomfortable talking about death and dying in general with their friends and family – 5% higher than the UK average and between 5-7% higher than each individual jurisdiction (Chart 4*). Compared to the UK average, the number of people selecting uncomfortable/very uncomfortable was higher in Northern Ireland for every item in this question – suggesting that, of all the jurisdictions in the UK, we have the biggest problem with talking about death and dying within social settings.

People's willingness to talk specifically about their end of life wishes with their doctors and nurses were more similar across the UK. In NI, 76% of people said they would be comfortable/very comfortable to have those discussions (Chart 5) – which was only slightly higher than the UK average (74%) and the proportion in England (73%) and Wales (75%).

The proportion of those selecting uncomfortable/very uncomfortable was broadly similar across the UK as well, although slightly higher in Northern Ireland than the overall average (12% vs 10%) – meaning that roughly one in eight people here would not be comfortable talking about their end of life wishes with their doctor or nurse.

Chart 5 How comfortable would you feel discussing your end of life wishes with your doctors and nurses?



23%

of people in Northern Ireland said they were uncomfortable talking about death and dying with their friends and family.

Finding support and information in the context of death, dying and bereavement

As we have seen, someone with high levels of death literacy will have context-specific knowledge about the death system where they live and, crucially, *the ability to put that knowledge into practice.* [2] Our survey assessed this knowledge-into-practice element in relation to two key areas – planning ahead for the end of life and accessing bereavement support when someone dies (Chart 6).

The results are, again, very concerning. Nearly a third (30%) of people in Northern Ireland disagreed/strongly disagreed with the statement 'I know where to find information on how to plan in advance for my care at the end of life'.

30%

of people in Northern Ireland don't know where to find information on advance care planning.

*See end of report (p18-19) for Chart 4

Public health approaches to palliative care

Public health approaches to palliative and end of life care seek to promote public openness around death, dying and loss; tackle the stigma that can surround these issues; and empower people, families and communities to draw on their own resources and community supports to adapt and cope with death and dying. [A]

There are a number of core tenants at the heart of these approaches, including community development, death education and partnership working between societal stakeholders such as schools, workplaces, churches and more. [B]

These approaches also help to extend the reach of end of life and bereavement services by engaging wider populations beyond those who are actively dying and their loved ones.

Examples of public health approaches in practice:

- The Cheshire Living Well, Dying Well programme delivered training to people in public-facing roles to engage their service users around issues of life, age, death and loss. The programme also delivered bereavement and grief training for students at the University of Chester. [C]

- St. Christopher's Hospice, London, developed programmes to raise awareness of dying and bereavement with local schools. Groups of students aged 9-16 visited the hospice and had the opportunity to talk to staff and patients about terminal illness and bereavement, helping to reduce anxiety and foster confidence in engaging with these issues. [D]

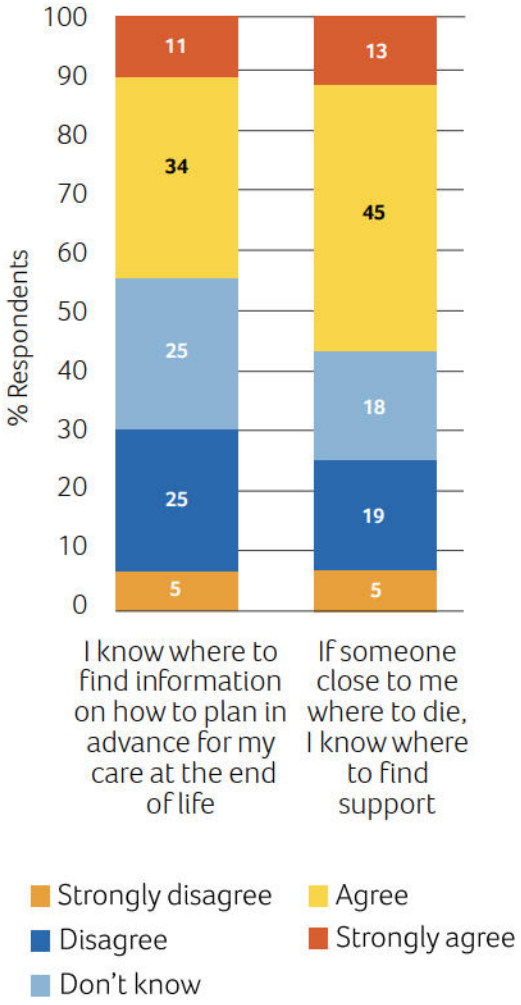
A Paul, S and Sallnow, L (2013). Public health approaches to end of life care in the UK: An online survey of palliative care services. BMJ Supportive & Palliative Care, 3 (2).

B Public Health Palliative Care International.

C Abel, J et al (2016). Each community is prepared to help: Community development in end of life care.

D Kelleher, A (2013). Compassionate communities: End of life care as everyone's responsibility. QJM, 106 (12)

Chart 6 To what extent do you agree or disagree with the following statements about the availability of information or services regarding end of life care?



When those who selected 'don't know' are added to this, it means over half (55%) of people failed to provide an affirmative answer to the question.

Local survey respondents performed slightly better in this question than the UK average, with 46% of people in Northern Ireland saying they agreed/strongly agreed that they knew where to find information on advance care planning, compared to 44% across the UK as a whole. Rates were the same in Scotland (46%) and higher in Wales (47%).

Our findings still suggest, however, that more than a decade after the Department of Health's Living Matters, Dying Matters Strategy highlighted the importance of accessible information to support meaningful future end of life care planning in Northern Ireland [21], too many people still do not know where to find this information.

Regarding bereavement support, nearly a quarter (24%) of people in Northern Ireland disagreed/strongly disagreed with the statement 'if someone close to me were to die, I know where to find support'. When the 'don't knows' are added, this means over 40% of people did not provide an affirmative answer to the question.

As above, there are some positives to take, as the proportion of people who selected agree/strongly agree to this question was slightly higher in Northern Ireland (58%) than the UK average (54%) and the four jurisdictions individually (England 53%, Scotland 54%, Wales 56%).

However, outperforming a low benchmark is not a cause for celebration. With evidence suggesting that those who receive insufficient bereavement support are more likely to experience a worsening of physical and mental health, [22] there is clearly a lot of work to do to ensure more people in Northern Ireland are aware of the bereavement support available where they live.

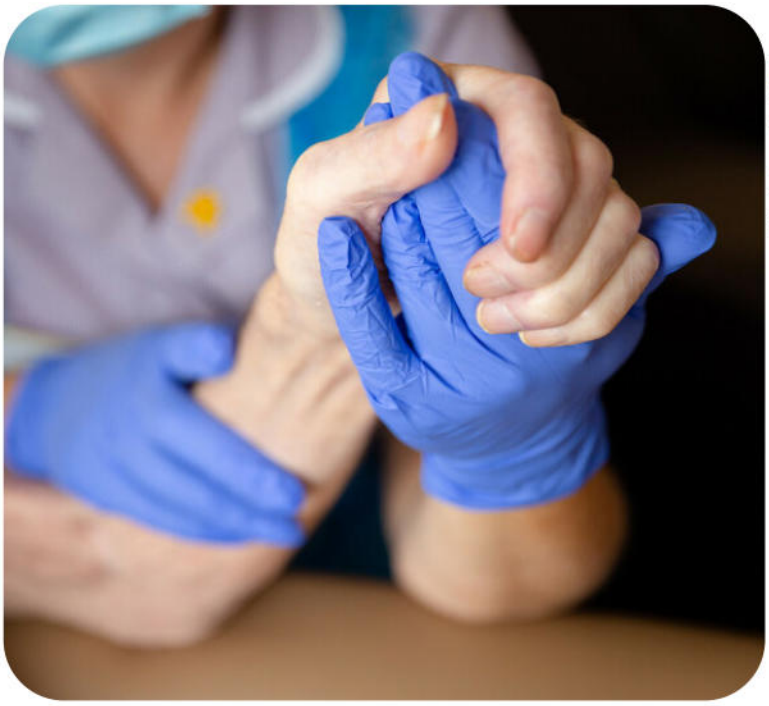
Time is running out to tackle Northern Ireland's death literacy problem

Our survey findings show that there are numerous important gaps in Northern Ireland's death literacy levels. Demographic trends here suggest there has never been a more important time to begin addressing them.

Like many of our neighbours, Northern Ireland's population is ageing rapidly, with growing numbers of people living longer with multiple chronic or terminal health conditions and complex needs. During the period 2010/11-2020/21, the number of people on Northern Ireland's Palliative Care Register doubled, [23] while deaths from cancer, chronic lower respiratory diseases and dementia alone increased by 10%, 17% and a staggering 65% respectively. [24]

Looking to the future, demand for palliative care is expected to grow by over 30% by 2040, [25] with the number of people dying each year growing by nearly a fifth during this time. [26]

In this context, it is imperative that death literacy is given much greater prominence on the agendas of policymakers and health and social care leaders. Failure to tackle the death illiteracy that exists in large parts of Northern Ireland's population will have serious consequences for the end of life experience of thousands of local people in the years ahead.



Philip Hardman/Marie Curie

Recommendations for policymakers and health and social care leaders

This report has shown that, while Northern Ireland is not an entirely death illiterate society, some sections of the population could benefit from greater understanding and awareness of key issues related to death, dying and bereavement. At present, there are too many people unprepared for the end of life and reluctant to discuss or plan for it. Others are comfortable talking about these topics, but are unaware of where and when they can access support when they need it.

These are critical challenges to overcome. The following recommendations, while by no means exhaustive, can help policymakers and health and social care leaders to begin addressing Northern Ireland's death literacy gaps:

- As part of a public health approach to palliative care, the Department of Health should commission an **action plan for promoting death literacy** across Northern Ireland. This should utilise co-design/co-production models involving all stakeholders and sectors with a role to play in raising awareness and understanding of issues of death, dying and bereavement (e.g. workplaces, religious groups, community organisations, schools etc. – see international examples on page 14). Funding should be attached to the action plan to ensure these stakeholders have the resources and capacity they need to play a full role in meeting its objectives. Development of the action plan would, ideally, be a dedicated workstream under a new **palliative care strategy for Northern Ireland.**

- Death education programmes should be included in relevant parts of the school curriculum in Northern Ireland, as part of a life-course approach to teaching children and young people about death, dying and bereavement. These programmes should be designed by the Departments of Health and Education and the Council for the Curriculum, Examinations and Assessment (CCEA), following international evidence and best practice.

- The Department of Health's new **Advance Care Planning Policy** should be finalised as a priority in the next Assembly mandate, with any required funding provided in full.

- Modules/courses on promoting death literacy among patients and their loved ones should be part of **training and Continuing Professional Development** for relevant health and social care disciplines. This should include nursing, Allied Health Professions, social work and more.

- A benchmarking exercise should be carried out to assess the accessibility and quality of information materials on core death literacy issues in every statutory health and social care setting in Northern Ireland. Where they are not available already, **information packs** covering key themes – including details on palliative and end of life care services, the importance of discussing death and dying with loved ones and signposting to bereavement support – should be distributed.

- **Further research** should be commissioned to explore death literacy challenges in Northern Ireland and design the evidence-based interventions required to address them. This should include a specific research focus on if/how public health interventions can improve death literacy.

- A representative **annual survey** should be carried out to measure progress and monitor trends on death literacy levels among the Northern Ireland population.

Developing death literacy: International examples

Death literacy among young people: Calvary Health Care Bethlehem schools project, Australia

In 2015 an immersion programme in palliative care was developed at Calvary Health Care Bethlehem, a public hospital specialising in palliative care and neurology, for Year 10 students at a girl's college in Oakleigh, Australia. The students interviewed a range of healthcare staff and spent time with patients. These activities supplied visual and narrative material for the development of a DVD resource, which was used as part of classroom death education sessions. A project evaluation found that:

- Most participants developed a new or deeper understanding of death and palliative care.
- Almost half of the participants described a decreased fear of death.
- Nearly half of the participants reported increased feelings of confidence in talking about death, dying, palliative care, grief and loss.
- Some described being able to speak for the first time about end of life issues with family and friends, while others spoke about being able to have these conversations more easily or with greater confidence. [27]

Death literacy through digital resources: Dying2Learn mass online course

In 2016, clinical and academic palliative care experts from Australia developed and launched a global online course aiming to foster community death conversations and build awareness of palliative care and other issues of death and dying. The course content explored themes including how care practices for dying people have changed over time, the role of medicine in how we die and how society engages with death. Participants from around the world accessed videos and articles on these subjects, completed online activities and interacted with each other via discussion boards.

An evaluation of the project found that mean scores on death competence – which includes many of the key death knowledge and skills themes set out in page 4 above – increased between the beginning and end of the course, with participants perceiving themselves to be better prepared to cope with the occurrence of death in their lives. The course was beneficial for all participants regardless of whether they had previously experienced a personal bereavement. [28]

iStock

Contributors and acknowledgments

This report was written by Marie Curie's Northern Ireland Policy and Public Affairs Team, with the support of colleagues from the School of Psychology, Queen's University Belfast, and the Marie Curie Palliative Care Research Centre and Division of Population Medicine, Cardiff University. The survey on which it is based was designed and delivered by a research partnership involving these three organisations.

Report contributors:

- **Craig Harrison** Marie Curie Policy and Public Affairs team
- **Dr Lisa Graham-Wisener** School of Psychology, Queen's University Belfast
- **Joan McEwan** Marie Curie Policy and Public Affairs team
- **Prof Annmarie Nelson** Marie Curie Palliative Care Research Centre, Cardiff University
- **Dr Emma Berry** School of Psychology, Queen's University Belfast
- **Prof Martin Dempster** School of Psychology, Queen's University Belfast
- **John Shayegh** School of Psychology, Queen's University Belfast
- **Dr Anthony Byrne** Marie Curie Palliative Care Research Centre, Cardiff University
- **Dr Ishrat Islam** PRIME Centre Wales, Cardiff University

We are grateful to the members of the public in Northern Ireland who took the time to complete the survey and share their views with us.

Philip Hardman/Marie Curie

References

1 For an overview of the survey findings across the UK see: Marie Curie (2021). Public attitudes to death and dying in the UK.

2 Noonan, K et al (2016). Developing death literacy. Progress in Palliative Care, 24 (1).

3 Leonard, R at al (2020). Death Literacy Index: A report on its development and implementation.

4 Sallnow, L et al (2022). Report of the Lancet Commission on the value of death: Bringing death back into life. The Lancet.

5 NHS. Content style guide: Health literacy. See: https://service-manual.nhs.uk/content/health-literacy.

6 Prince-Paul, M and DiFranco, E (2017). Upstreaming and normalising advance care planning conversations: A public health approach. Behavioural Sciences, 7 (18).

7 For more information and further reading on public health approaches to palliative and end of life care, see: All Ireland Institute of Hospice and Palliative Care (2017). Briefing paper: Public health approaches to palliative care.

8 Breen, L J et al (2020). Grief literacy: A call to action for compassionate communities. Death Studies.

9 Colinns, A et al (2020). Community knowledge of and attitudes to palliative care: A descriptive study. Palliative Medicine, 34 (2).

10 Marie Curie and Carers NI (2018). Lost retirement: The impact on older people of caring for someone with a terminal illness.

11 Brinkman-Stoppelenburg, A et al (2014). The effects of advance care planning on end-of-life care: A systematic review. Palliative Medicine, 28 (8).

12 Miller-Lewis, L et al (2020). Can exposure to online conversations about death and dying influence death competence? An exploratory study within an Australian massive open online course. OMEGA – Journal of Death and Dying, 81 (2).

12 Llewelly, R et al (2016). Cracking open death: Death conversations in primary care. Journal of Primary Health Care, 8 (4).

13 Department of Health (2021). Advance Care Planning Policy for adults in Northern Ireland: Draft policy for publication consultation.

14 Claire, S E (2003). Loss and grief in General Practice: The development and evaluation of two instruments to detect and measure grief in General Practice patients. Available at: https://digital.library.adelaide.edu.au/dspace/handle/2440/37929.

15 Childhood Bereavement Network (2016). Key estimated statistics on childhood bereavement. Available at: https://childhoodbereavementnetwork.org.uk/sites/default/files/uploads/files/Key-statistics-on-Childhood-Bereavement-Nov-2016.pdf.

16 Smith, D E and Hunter, S B (2008). Predictors of children's understandings of death: Age, cognitive ability, death experience and maternal communicative competence. OMEGA – Journal of Death and Dying, 57 (2).

17 VotesForSchools (2022). Report: Should learning about coping with loss and bereavement be included on the school curriculum? Available at: https://www.votesforschools.com/site/assets/files/1812/220114_-loss_bereavement_-_data_report_2.pdf.

18 Paul, S (2019). Is death taboo for children? Developing death ambivalence as a theoretical framework to understand children's relationship with death, dying and bereavement. Children & Society, 33.

19 Etheridge, Z and Gatland, E (2015). When and how to discuss 'do not resuscitate' decisions with patients. BMJ, 350.

20 Department of Health (2010). Living Matters, Dying Matters: A palliative and end of life care strategy for adults in Northern Ireland.

21 Anoun, S M et al (2020). The impact of bereavement support on wellbeing: A comparative study between Australia and Ireland. Palliative Care and Social Practice, 14.

22 Department of Health. Raw disease prevalence trend data.

23 Northern Ireland Register General. Annual report cause of death data.

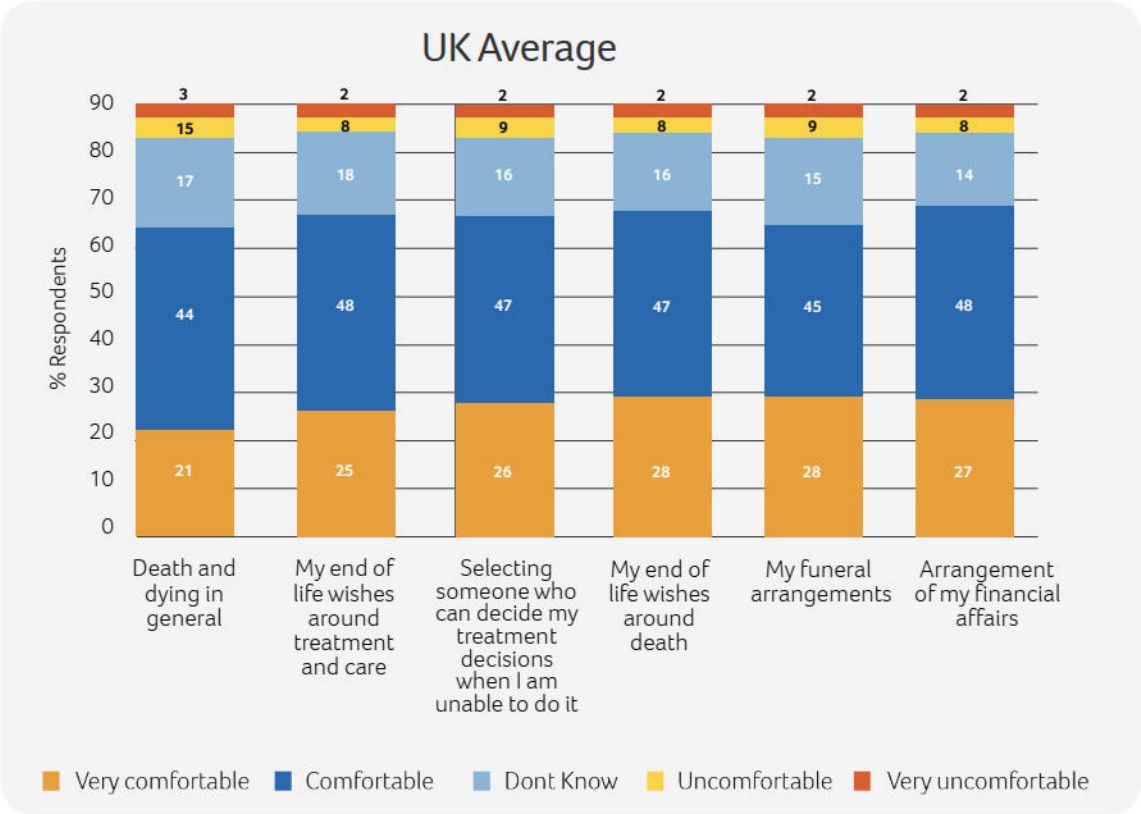
24 Palliative Care in Partnership programme.

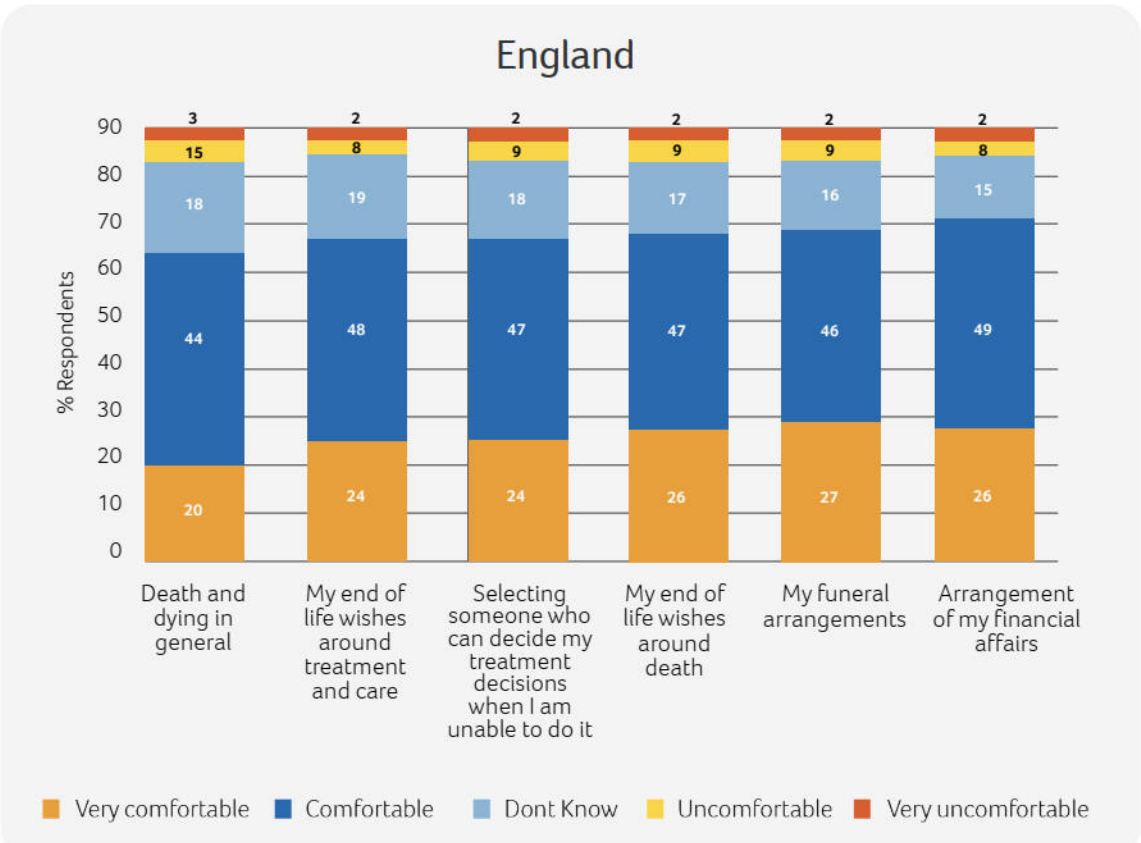
25 Northern Ireland Statistics and Research Agency (2019). 2018-based population projections for Northern Ireland.

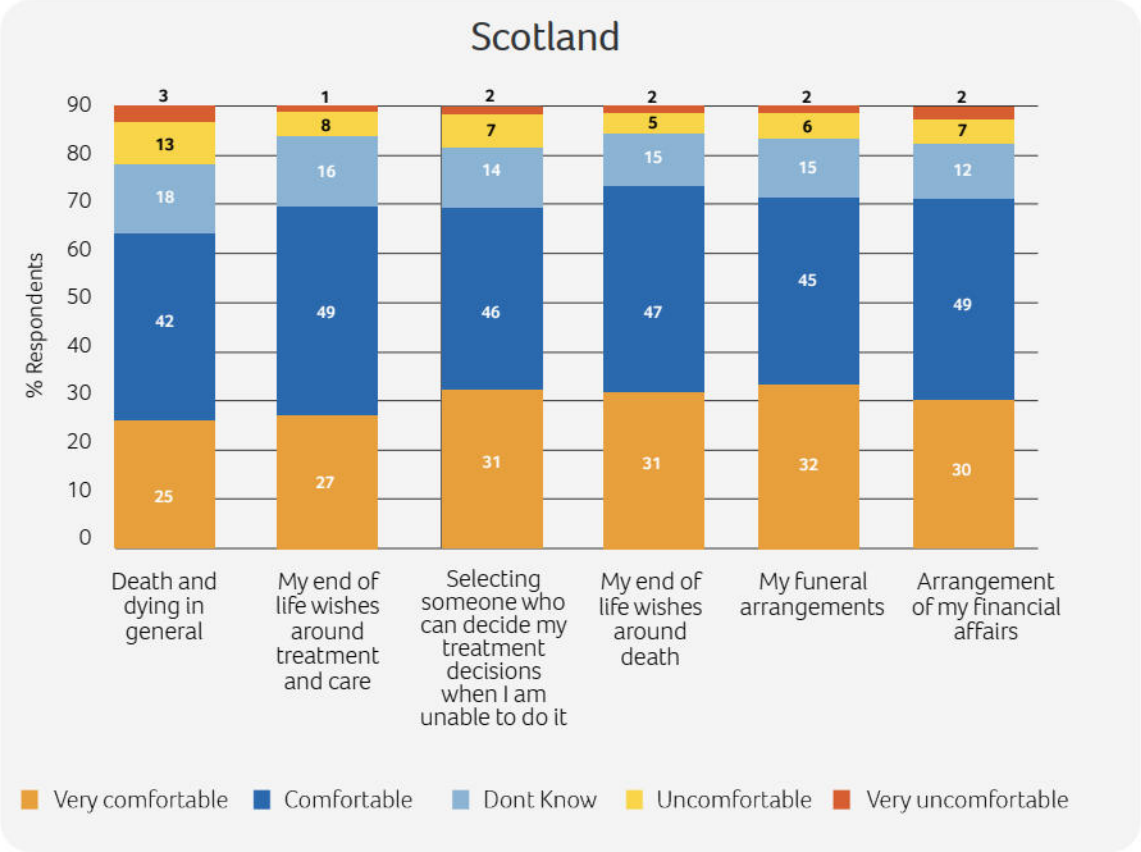
26 Grindrod, A and Rumbold, B (2015). Ensuring Support from Communities site evaluation report 2013-2015: Calvary Health Care Bethlehem 'The Schools Project'.

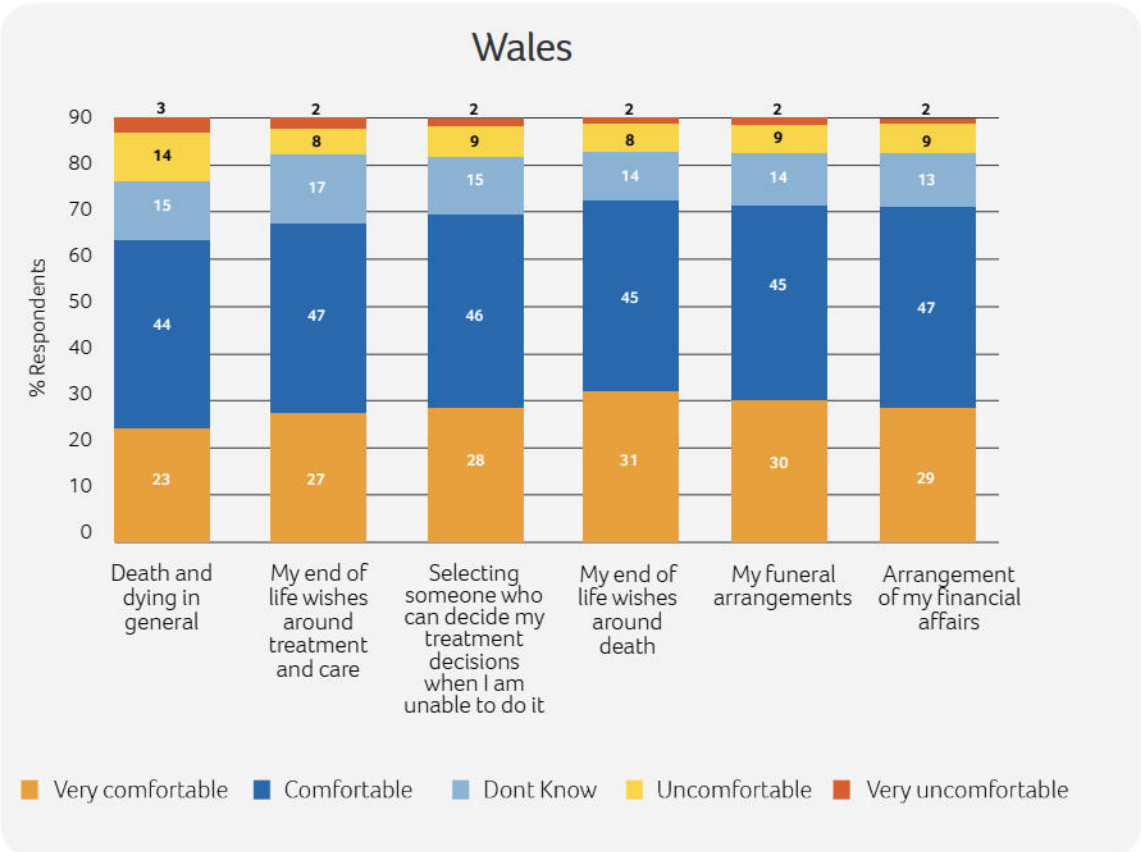
27 Miller-Lewis, L et al (2020). Can exposure to online conversations about death and dying influence death competence? An exploratory study within an Australian massive open online course. OMEGA – Journal of Death and Dying, 81 (2).

Chart 4 How comfortable would you feel discussing the following topics with your family and friends?






Scotland
% Respondents
90
80
70
60
50
40
30
20
10
0
3
13
18
42
25
1
8
16
49
27
2
7
14
46
31
2
5
15
47
31
2
6
15
45
32
2
7
12
49
30
Death and dying in general
My end of life wishes around treatment and care
Selecting someone who can decide my treatment decisions when I am unable to do it
My end of life wishes around death
My funeral arrangements
Arrangement of my financial affairs
Very comfortable
Comfortable
Dont Know
Uncomfortable
Very uncomfortable


Wales
% Respondents
90
80
70
60
50
40
30
20
10
0
3
14
15
44
23
2
8
17
47
27
2
9
15
46
28
2
8
14
45
31
2
9
14
45
30
2
9
13
47
29
Death and dying in general
My end of life wishes around treatment and care
Selecting someone who can decide my treatment decisions when I am unable to do it
My end of life wishes around death
My funeral arrangements
Arrangement of my financial affairs
Very comfortable
Comfortable
Dont Know
Uncomfortable
Very uncomfortable

For more information contact:

Craig Harrison
Policy Manager, Marie Curie
Northern Ireland

E: **craig.harrison@mariecurie.org.uk**

Thank you to everyone who supports us and makes our work possible. To find out how we can help or to make a donation, visit our website mariecurie.org.uk

Charity reg no. 207994 (England & Wales), SC038731 (Scotland) H902