Ulster University

Where Are We Now? - Examining public knowledge and attitudes towards palliative care and advance care planning in Northern Ireland

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INTRODUCTION

Palliative care is defined as an approach to address the problems associated with life-threatening illness by means of early identification, assessment and treatment of physical, psychosocial and spiritual problems (1). The World Health Organisation (WHO) (2) advocate that palliative care should be considered as a public health issue, with access to such care considered a human right (3,4). More recently, the WHO in its sixty-seventh World Health Assembly in May 2014, urged member states to develop, strengthen and implement palliative care policies that would integrate palliative care services in the continuum of care, across all levels (5). This strategic shift in palliative care from that of a service designed to address the needs of those with advanced cancer in the last weeks and days of life, to a more ‘integrated’ approach across the spectrum of chronic life limiting illness, has the potential to contribute towards the quality of care of all citizens. Furthermore, the evidence base for the support of such an ‘integrated’ approach to care is increasing (6–10). Despite this, however, current patterns of usage continue to indicate that palliative care is accessed late in the course of illness (11). In addition, whilst end of life planning, commonly referred to as advance care planning, is advocated in policy, research would suggest there are wider societal factors which may limit patient and wider community access to advance care planning and ‘early’ palliative care.

Globally, the demand for palliative care is increasing and it has been estimated that over 20 million people would benefit from basic palliative care annually (12). A recent Lancet Commission, using health related suffering as a marker of need for palliative care, estimated that by 2060 48 million people will die with serious health related suffering, increasing more rapidly among the older population aged 70 years plus (13). A similar picture is noted for Northern Ireland. For example, based on mortality data and using the approach for population needs assessment (NECPAL tool) (14), it has been estimated that the population need for palliative care in Northern Ireland is predicted to increase by 31% by the year 2040 (15).

However, despite this projected need, international research over the last decade suggests that not only is palliative care poorly understood among the public and community members more broadly, but that misperceptions continue to exist (16–20).

For example, a recent cross-sectional survey in Australia (n=421) reported a median of at least three misperceptions of palliative care. This points to a gap in knowledge, which may impact on future access to quality care in the event of a serious illness (21). It is unsurprising, therefore, that this need to raise awareness and understanding of palliative care and advance care planning amongst the public, within a public health approach to palliative care, has been recognised as a key policy priority, internationally (16,18–20), nationally (17,22), and regionally (23,24).

A range of terms have been used to describe a public health approach to palliative care, including compassionate cities, compassionate communities, health promoting palliative care, community development, engagement or participation (25). Furthermore, there remains debate within the academic literature around various 'models' and conceptual underpinnings for this approach.

A public health approach to palliative care has been broadly defined as

> "*a health promotion approach to end of life care, one that views the community as an equal partner in the long and complex task of providing quality health care at the end of life. Just as health, according to WHO, is 'everyone's responsibility' so too is death, dying, loss and care"* (26).

Specifically, the Department of Health have outlined an agreed definition which notes that a public health approach to palliative care

> *"recognises the role of society and community in enabling and supporting people living with life-limiting conditions, and those important to them, to live well with flexible, holistic and person-centred care based on positive and collaborative partnership.*
> *This approach will involve working collaboratively to:*
> *(1) Increase awareness, understanding and discussion around palliative care through education and information;*
> *(2) Create and enhance networks across communities and sectors to support people living with a life limiting illness and those important to them; and*
> *(3) Encourage people to think about and plan for their future physical, emotional, social, financial and spiritual needs* (27).

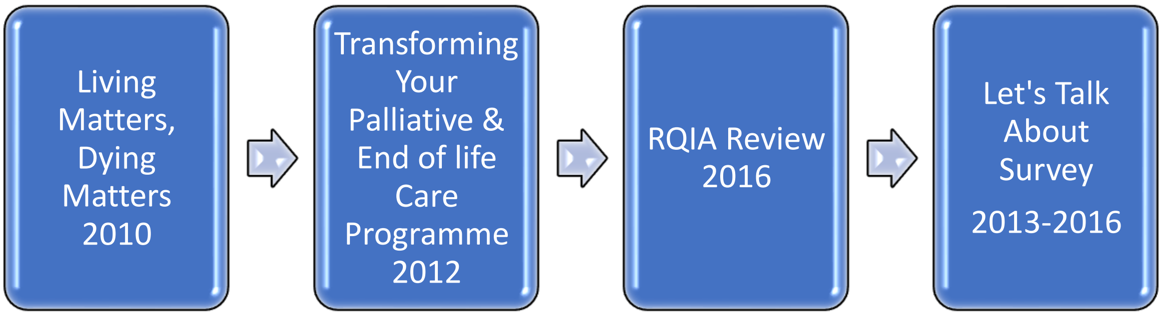
From the literature is it noted that there are 3 overlapping approaches to public health and palliative care:

- WHO approach (practice-driven)
- Health promotion approach (community assets)
- Population based approach (epidemiology) (28)

Northern Ireland Context

In Northern Ireland from 2016, a range of engagement exercises and several strategic drivers led by the Regional Palliative Care Programme (RPCP) – 'Palliative Care in Partnership' have been informed by a number of strategic drivers. Some examples of strategic drivers are outlined in figure 1.

Figure 1 – Key Strategic Drivers



Alongside this, the Department of Health report, Health and Wellbeing 2026: Delivering Together Plan reinforced the need for a public health approach which will expand and develop the role of the community and voluntary sector in delivering palliative and end of life care in Northern Ireland (29). Within the NI context, various initiatives developing/demonstrating elements of a public health approach to palliative have been developed. These include for example the `Heart of Living and Dying'(HDL) initiative developed by a social worker in the Southern Trust which is being delivered regionally (30). HLD is a facilitated two-hour group process which brings advance care planning into the public domain where members of the public are invited to participate in a supported conversation about what matters to them in their living and dying and to begin to plan ahead.

In the Northern Health and Social Care Trust, `End of Life Companion' services are being delivered to provide support for patients, families and loves ones in need of support and reassurance, in the last days of life. Finally, the `Compassionate Communities North West' (31) initiative is working towards changing attitudes and behavior towards life, age, death and loss.

However, previous research by McIlfatrick (23) examining the level of awareness and attitudes towards palliative care among Northern Ireland's general public, reported an overall lack of awareness and a lack of familiarity of what palliative care means. Similarly, research exploring the views and experiences of service users and carers of palliative care services in the Republic of Ireland and Northern Ireland reported the biggest worry was planning for the future (24). A review of the implementation of the Living Matters Dying Matters strategy (32), highlighted that whilst many initiatives have been developed to raise awareness, there remains a significant lack of understanding, with the need for a coordinated approach to raising public awareness about palliative and end of life care (33). The review recommended that raising public awareness of palliative and end of life care should be a core component of any new action plan. Thus, there is a need for further work to examine public knowledge of and attitudes towards palliative care and advance care planning; in order to inform a future action plan and the potential role that any future educational interventions and information could play in addressing this.

AIM AND OBJECTIVES

Research Aim:

The research aimed to explore the awareness, knowledge and public views and behaviour in relation to palliative care and advance care planning and identify strategies to raise awareness within a public health framework.

Research Objectives:

The objectives of the research are to identify:

1. awareness, knowledge, and views about palliative care and advance care planning among the public
2. influencing factors in the provision of palliative care and advance care planning and best practice
3. behaviour among the public regarding holding discussion and making advance care plans; and
4. strategies to raise awareness within a public health framework.

METHODOLOGY

In this section, the methodological and ethical procedures will be described. Data for the study were collected over two phases employing both qualitative and quantitative methods.

Phase 1: Northern Ireland Life and Times Survey

This phase comprised completion of the already established large-scale survey, the Northern Ireland Life and Times (NILT) annual survey (34). The palliative care and advance care planning section of the NILT survey was based on the Palliative Care Knowledge Scale (PaCKS), a thirteen item, true/false format instrument. Eight Items relating to participants' attitudes towards advance care planning were informed by European Association of Palliative Care White Paper on advance care planning and were responded to using 5-point Likert scale. There were also six yes/no items on participants' prior knowledge of palliative care. There were a further two yes/no response items on knowledge of advance care planning, as well as a question allowing participants to detail who they had previously discussed advance care planning with (9 options).

Participants included a random representative sample of adults from the NI population aged 18 years and over (using Postal Address file). The surveys were completed in the respondents' home, face-to-face and on first contact, using the 'next birthday' method. The total achieved sample was 1,201 interviews (response rate 56%). All data were analysed using SPSS software programme. Descriptive and inferential statistics were undertaken**.** Ethical approval was granted from the School Research Ethics Committee (SREC) at the School of Social Sciences, Education and Social Work at Queen's University Belfast. This is renewed/extended each year with re-applications every 3 years.

Those who completed the survey were then asked if they wished to contribute further to the research and those who agreed were invited to take part in a series of focus groups and one-to-one interviews.

Phase 2: Key Stakeholder Interviews and Focus Groups

This phase involved a series of one to one in-depth interviews (n=19) and focus groups (n=2) undertaken with a sample of the NI population who had previously completed the NILT survey and had given their permission to be contacted by researchers to take part in further research. Participants were also asked to complete a short questionnaire at the beginning of the interviews to enable the research team to describe the characteristics of those who participated. These questions included variables such as age, gender, religion, level of education, behaviour relating to advance care planning and experience of palliative care.

The interview schedule comprised of 5 broad topic areas, which included questions on the participants' general knowledge of palliative care and advance care planning; whether they would seek knowledge and information on advance care planning and palliative care; their perceived accessibility of advance care planning /palliative care services and finally future strategies including supporting and inhibiting factors for promoting public awareness of palliative care/ advance care planning. Focus groups/ interviews lasted approximately 40-60mins and were recorded with the participant's permission; verbatim transcripts, once cleaned and checked, were subject to thematic content analysis using NVivo.

Ethical Approval was obtained prior to the qualitative research from Ulster University, Institute of Nursing and Health Research & School of Nursing Research Governance Filter Committee.

Personal and Public Involvement

Conducting focus groups and interviews with members of the NI public greatly improved the outcomes of the study as it afforded members of the public the opportunity to contribute to the research and to have a voice. Consultation with various organisations such as AIIHPC, Voices4Care, Palliative Care in Partnership, and PHA was ongoing throughout the project and their input was invaluable in refining the content of the quantitative survey tool.

FINDINGS

This chapter is divided into two parts to present the different phases of the research project.

Phase 1: Northern Ireland Life and Times Survey

Description of the Sample

A total of 1201 participants completed the NILT survey (response rate 56%). The participants were aged between 18 and 95 years (mean: 61yrs). The largest proportion of the population, 17.7%, were aged between 45-54years. Over half were female (58.3%); most were white (95.5%) and born in Northern Ireland (84.2%). Over two fifths of those surveyed were married (43.3%), described the area where they lived as a 'small city or town' (41.5%) and were protestant (43.9%). Regarding participant's level of educational attainment; over a quarter (25.3%) indicated that they had a degree or higher qualification, and just under a quarter (24.7%) reported no formal qualifications (see Table1, Appendix 1).

Prior Knowledge of Palliative Care

Of those who completed the NILT survey, almost half of participants (44.6%) had some direct experience of palliative care through a friend/relative. Approximately one in ten people surveyed (11.2%) had a job that involved working with people who received palliative care and three participants (0.3%) were currently receiving palliative care. A fifth of participants (20.1%) indicated that they had previously heard about palliative care from either TV, newspapers or social media, with a further 9% acknowledging that they had heard the term from another source including through school/university, word of mouth, from a friend/relative, or from a medical practitioner. 13.8% had heard of the term palliative care but were unsure or couldn't remember where they had the term. Only 14.2% of participants indicated that they had no prior knowledge of the term palliative care.

Understanding of Palliative Care

Individual items from PaCKS were answered correctly between 44.6% and 72.4% of the time. Overall, just over a fifth of participants (22.6%) were completely accurate in their understanding of palliative care, scoring a total of 13 out of 13 items correctly. Similarly, just under a fifth (19.5%) answered none of the items correctly.

Table 2 – Participant's responses to PaCKS items on Knowledge of Palliative Care

Palliative Care Items (PaCKS)	Correct n (%)	Incorrect n (%)
A goal of palliative care is to address any psychological issues brought up by serious illness (T)	694 (57.8%)	507 (42.2%)
Stress from serious illness can be addressed by palliative care (T)	760 (63.3%)	441 (36.7%)
Palliative care can help people manage the side effects of their medical treatments (T)	863 (71.9%)	338 (28.1%)
When people receive palliative care, they must give up their other doctors (F)	759 (63.2%)	442 (36.8%)
Palliative care is exclusively for people who are in the last 6 months of life (F)	536 (44.6%)	665 (55.4%)
Palliative care is specifically for people with cancer (F)	776 (64.6%)	425 (35.4%)
People must be in the hospital to receive palliative care (F)	812 (67.6%)	389 (32.4%)
Palliative care is designed specifically for older adults (F)	812 (67.6%)	389 (32.4%)
Palliative care is a team-based approach to care (T)	850 (70.8%)	351 (29.2%)
A goal of palliative care is to help people better understand their treatment options (T)	796 (66.3%)	405 (33.7%)
Palliative care encourages people to stop treatments aimed at curing their illness (F)	730 (60.8%)	471 (39.2%)
A goal of palliative care is to improve a person's ability to participate in daily activities (T)	726 (60.4%)	475 (39.6%)
Palliative care helps the whole family cope with a serious illness (T)	870 (72.4%)	331 (27.6%)

The mean PaCKS score was 8.31 (standard deviation [SD] = 4.91, range 0-13). Examination of the variability in scoring on PaCKS found the following statistically significant results.

- Respondents with higher levels of education had better knowledge of palliative care.
- Results indicated that females had significantly higher palliative care knowledge scores than males.

- Marital status had a significant impact on PaCKS scores. There was a significant difference in knowledge scores between those who were single and those who were married and living with husband/wife (p=<0.001), with married people have a better knowledge score than those who were single. There was also a significant difference between those who were married and living with husband/wife; they scored higher when compared to those who were married and separated from husband/wife (p=<0.001), and those who were widowed (p=<0.001).
- Knowledge of palliative care also increased with age – to a point at 55-64 years of age then decreased thereafter. An ANOVA revealed a significant difference across age [F (7,1180) =9.193, p=<0.005], with post hoc tests revealing that there were significant differences in knowledge scores between younger and older populations, for example, those aged 18-24yrs scored significantly lower than those aged 45-54yrs (p=<0.005).
- Country of birth had a significant impact on PaCKS scores. An ANOVA revealed a significant difference across country of birth [F(3,1197)=8.266, p=<0.0005], with post hoc tests revealing that there was a significant difference in knowledge scores between those born in England/Scotland/Wales and those born elsewhere (p=001), with those born in England/Scotland/Wales scoring better; as well as a significant difference between those born in Northern Ireland when compared to those born elsewhere (p=<0.001). Again those born in Northern Ireland scored higher than those born elsewhere.

Knowledge of Advance Care Planning

A total of 28.5% of respondents had heard of the term ‘advance care planning’ and only 7% had ever engaged in a conversation about it. The main source of discussion on advance care planning was from friends/family (3.3%); from G.P. (2.4%) and a member of the clergy (1.7%).

Attitudes to Advanced Care Planning

Table 3 – Participants' responses to Items on their Attitudes to Advance Care Planning

STATEMENTS	SA	A	N	D	SD	DK
I am in good health and do not want to think about preparing an advance care plan	25.4% (232)	37.9% (346)	15.6% (142)	16.3% (149)	3.4% (31)	1.3% (12)
It would comfort me to know I have left guidance about my wishes for my family(P)	27.1% (244)	54.1% (488)	10.8% (97)	4.4% (40)	0.4% (4)	3.2% (29)
I would worry I could not change my mind (N)	2.2% (20)	16.7% (150)	17.1% (154)	46.9% (421)	11.1% (100)	5.9% (53)
I trust my family to make the right decisions for me (P)	36.4% (327)	47.2% (424)	9.8% (88)	3.7% (33)	1.0% (9)	1.9% (17)
I cannot change what will happen in the future and so there is no point in planning (P)	4.0% (36)	18.3% (164)	21.1% (189)	42.7% (383)	11.0% (99)	2.9% (26)
It is difficult to know if my wishes will be respected (N)	2.7% (24)	13.5% (121)	14.5% (130)	50.2% (450)	16.4% (147)	2.8% (25)
I worry that if I make plans for my future care and treatment, doctors would stop treatment too soon (N)	1.8% (16)	11.9% (107)	17.0% (152)	48.9% (438)	12.5% (112)	7.9% (71)
Discussing my wishes would give me a sense of control (P)	23.7% (212)	55.0% (493)	11.4% (102)	5.9% (53)	0.6% (5)	3.5% (31)

As shown in table 3, almost two thirds (63.3%) of respondents felt they were in good health and did not want to think about advance care planning. However, almost four fifths (82.2%) of respondents felt it would be comforting to know they had left wishes with their family and 66.4% felt that their wishes would be respected. Respondents were generally sure that making advance care plans would not have a negative impact on the quality of care they received and 86.6% of respondents trusted their family to make the right decision for their care. All respondents were asked if they would like to find out more about advance care planning and almost two thirds (68.3%) said no.

Phase 2: Key Stakeholder Interviews and Focus Groups

This section outlines the key themes that emerged from interviews and focus groups with stakeholders. In total, three themes were derived, which reflect the language used by the participants. The three themes are: Awareness and understanding of Palliative Care and Advance Care Planning; Barriers and Facilitators to promoting public awareness; and Future strategies to improve understanding of Palliative Care and Advance Care Planning. For contextual purposes, participants also completed a brief questionnaire to record demographics and establish their level of knowledge relating to palliative care and advance care planning.

Participants' Demographics

A total of 25 participants contributed to the qualitative phase of the research. Almost all the participants (96%) were white; 60% were male and nearly three quarters (72%) were married or co-habiting. Less than a quarter (24%) of those who contributed to the qualitative research were under 50 years, with the largest proportion of participants (36%) aged between 61-70 years. Almost half (48%) were retired, and all participants were Christian (48% catholic, 40% protestant, 12% other Christian).

Table 4 – Participants' Demographics

Demographics	(n) %	Demographics	(n) %
Gender		**Ethnic origin**	
Male	15 (60%)	White	24 (96%)
Female	10 (40%)	Black African	1 (4%)
Age		**Marital status**	
30-40	1 (4%)	Married	15 (60%)
41-50	5 (20%)	Separated	2 (8%)
51-60	7 (28%)	Divorced	2 (8%)
61-70	9 (36%)	Cohabiting	3 (12%)
71 plus	1 (4%)	Single (never married)	1 (4%)
Not answered	2 (8%)	Widow/Widower	1 (4%)
		Other	1 (4%)
Employment status		**Religious affiliation**	
Retired	12 (48%)	Catholic	12 (48%)
Employed	8 (32%)	Protestant	10 (40%)
Unable to work	3 (12%)	Other Christian	3 (12%)
Self employed	2 (8%)		

Theme 1: Awareness and Understandings of Palliative Care and Advance Care Planning

Dearth of Knowledge & Misconceptions linked to Terminology

Over half (60%) of the participants indicated that they were aware and had some prior knowledge of palliative care. One in five (20%) indicated that they had a lot of knowledge of palliative care and the same number indicated that they had no previous knowledge of the term palliative care. Many believed palliative care to be complex, specialised care, that was offered at `the very end' when there was 'no hope', or no other 'treatments' available. This led many to interchange the term palliative care with 'end of life care' or care for the 'terminally ill'. Such care was perceived to be delivered by specialist and generalist healthcare professionals such as the GP, hospital doctors and nurses, hospice nurses, social workers etc. However, many could not articulate the components of a palliative care service nor the various individualised care packages and the range of support that could be offered.

When asked about advance care planning, almost half (44%) were unaware of the term. This even applied to those participants who had caregiving experience. When questioned many admitted they were unsure of how best to plan or support someone through a terminal illness with most viewing advance care planning as a 'last resort' when all treatment had failed. Advance care planning was perceived to be an 'insurance', describing it as a 'legal document', 'will' or 'contingency plan' intended to act as a buffer against life events relating to their health.

> *'…I suppose putting in place, a plan for what sort of care you might need, different circumstances, different health issues… for a service to be available when needed and be locally accessible and available quickly…'* (PCACPI010)

Understanding based on Previous Experience

Participants acknowledged diverse sources of information in relation to finding out about palliative care and advance care planning, including online, media, friends and family, healthcare professionals and religious and social service providers. Over three quarters (76%) of participants had a close relative/friend who had required access to palliative care. Most drew on their lived experiences of caring for someone at the end of life, or exposure to death as key sources of information upon which they built their understanding. Yet, many described their experience of end of life care as being ‘traumatic’ or as having ‘happened very fast’ in which learning occurred in an ad-hoc sporadic manner. Whilst participants welcomed the opportunity to speak about their experiences they also drew and learnt from others during the study, within a safe environment. Palliative care was believed to be focused on medication in the final stages of death and resuscitation options, noting that ‘a good death’ and ‘dying comfortably’ were the optimum goals.

When discussing their personal experience if was found that none of the participants who took part within the qualitative phase had put an advance care plan in place. Whilst some had revealed that they had started to think about their future care, most found the subject difficult to broach with loved ones or healthcare professionals. Only one participant had been offered the opportunity to talk about advance care planning. Others refused to think about such matters believing that such conversations were not necessary unless prompted and rationalised, by a ‘health scare’ or diagnosis of a terminal illness or disease. Therefore, advance care planning was focused on funeral wishes and treatment options once a terminal illness had been confirmed or diagnosed. These narrow views on palliative care and advance care planning led many to dismiss the idea of discussing death and dying as a common or normal conversation to have with family or indeed health care professionals as a matter of course, with over three quarters (76%) indicating that they had never discussed advance care planning with either family/friends.

Theme 2: Barriers and Facilitators to promoting public awareness of Palliative Care and Advance Care Planning

Personal and Social Challenges

Many participants highlighted that palliative care and advance care planning are difficult subjects to broach, viewing them as a ‘taboo’ subject. It was recognised that even in today’s forward-thinking society, individuals are constrained in approaching such topics due to a fear of causing ‘upset or distress’ or fear by speaking about ‘their own mortality’. One participant stated;

> *‘…it’s never really talked about to be quite honest…like deaths and funerals – nobody really likes to envisage the end… it’s inevitable at some stage, but it’s*

> *sort of you don't talk about it, it's not going to happen, so to speak'.* (PCACPI003)

Participants alluded to this idea that life was 'hectic' and 'busy' and there are so many 'priorities' that palliative care and advance care planning are not thought of or prioritised until a 'health crisis is looming'. Regarding the importance of advance care planning, one stated;

> *'…I definitely do* [think advance care planning is important]*, but I think people are busy… it's actually about making the time…I haven't got around to it. I know I kind of need to and I know we all need to be prepared'.* (PCACPI007)

Some acknowledged that introducing the topic of palliative care and advance care planning among family and friends could be perceived as an indication of an impending problem - '*they'd start to think, is there something wrong with you?*' (PCACPI014); or could be viewed as depressing – '*you might be short of friends every time you start talking about death.*' (PCACPI016). However, participants also acknowledged that having a shared experience (being directly affected) often facilitated discussions about palliative care and advance care planning.

> '*I suppose whenever the people that you know are going through that process, then the terminology is used loosely, because you're in that circle' (*PCACPFG002).

Cultural Difficulties and Challenging Attitudes

Several participants reported how their religious views or cultural beliefs would influence, when, how and who they would approach to discuss palliative care and advance care planning issues. For many their religious or cultural beliefs would dictate the decisions they make in terms of their care, physical and spiritual (resuscitation, organ donation, cremation etc.). Others however believed that that if they didn't think about their own mortality, 'it's almost superstition', it won't happen.

A number highlighted the limitations of human knowledge and technological advancement, and that our actual time of death is beyond the scope of human prediction, therefore it shouldn't matter whether or not we talk about these matters.

> '…*the idea that there is no point almost in worrying about what was going to happen. If it's going to happen anyway*…' (PCACPI002).

Nevertheless, despite these beliefs, there was a recognition that challenging attitudes towards palliative care and advance care planning was important. The need to educate the public to realise and acknowledge their own mortality was vital in ensuring that they took responsibility for their own health and wellbeing, whilst they still have the capacity to do so. However, this was cushioned within generational differences, with a belief that older people may be more able to acknowledge their mortality, whilst younger generations viewed life as 'endless' or that somehow it wouldn't 'affect them'. Therefore, a tailored educational approach was needed to cater for the different generations' mind-set. As one participant stated;

> *'I think once you get to my age (67 years), or getting into your later life, you start to think of things like that (*advance care planning*), whereas …younger people are not really going to be interested'* (PCACPI008).

Lack of Information on Palliative Care and Advance Care Planning

All participants commented on the healthcare system and who they would approach if they needed more information, including their GP, a consultant if they were under the care of one, social worker, and specialist palliative care teams, such as those from a hospice setting.

Many believed that the NHS healthcare system was failing the public in terms of palliative care and advance care planning provision. There was an acknowledgment that with a growing and ageing population, the strains on the health service were increasingly apparent and they considered that patient care was suffering. Several issues were outlined including a perceived lack of knowledge and awareness by healthcare professionals of palliative care options and advance care planning; a lack of funding and resources within the health service to facilitate the growing need for palliative care and to promote the provision of advance care planning. Several participants commented that 'asking google' was their option for finding out about advance care planning. However, with reports in the media of false news and information they sometimes worried about the credibility of the information available online. One participant stated;

> *'…I don't think it's the government's right to say "this [medication] is too expensive, you can't have this treatment"…I think that they've [healthcare professional] been given an impossible remit by the government, because I think it is all about funding… that's very dangerous'* (PCACP00).

Theme 3: Future Strategies to Improve Understanding of Palliative Care and Advance Care Planning

Top-Down Leadership

When questions about how to move forward to enhance the public's awareness of palliative care and engagement with advanced care planning, participants vocalised the need for leadership. Although many had acknowledged that advance care planning was an 'individual responsibility', one equated the area of death to taxes.

> *'It's a bit like taxes, you know it's your responsibility to sort your taxes out, but the government manages the tax system and provides you with all the information you need to be able to sort out your taxes…So the reality is that there should be the same structure about end of life care…the government needs to take more responsibility in not necessarily providing the care, but providing the framework and the environment…'* (PCACPI004).

Other participants added that 'informing people' and opening opportunities for discussing advance care planning amongst families could be achieved easily with regular information drops (for e.g. information sent out to individuals on advance care planning when they reach a certain age). Another area discussed was the idea of building palliative care and advance care planning cover into existing life insurance schemes. One participant mentioned how driving licences asked about organ donation, thus opening the conversation to that younger population when they were applying for their licence. Similarly, if people had to think about advance care planning arrangements when they were sorting their life insurance, families would have an opportunity to discuss their wishes and start planning. All acknowledged the increasing need for funding for social care in order to provide palliative care for our growing (and aging) population, highlighting that ‘end of life problems occur to young and middle-aged people’ as well.

Participants also discussed the idea of creating a ‘pension pot for care’; highlighting that those who haven’t owned their home or who don’t have as much money may struggle. Some suggested transferring this burden to employers (as a mandatory obligation) or to the state government; where a specific pot of money could be used (in the same way as the current pension scheme) but with a specific focus on providing palliative care if required.

Increased Education and Information

All participants acknowledged there was a dearth of standardised lay information available for the public and recommended that more information should be provided about palliative care and advance care planning. Whilst the taboo around death and dying was recognised, in order to engage with people, it was recommended that we remove the barriers and fears that currently exist in people’s minds. This needs to be aligned with education and tailored information. Some specifically mentioned the idea of ‘a good death’ and dying in a ‘good way’, and that this is a concept that needs to be broached with everyone, irrespective of age or health status.

Participants discussed how disseminating information on palliative care and advance care planning could be done through a variety of platforms such as the localised methods; information in GP surgeries, libraries, posting leaflets and regionally incorporating media platforms (e.g. T.V., radio, newspapers and billboards). At a national level, there was much discussion about the benefit of weaving the topics into soap storylines, as a way of gearing people’s mind-set towards advance care planning and stimulate discussions that will ultimately sensitise people to the areas of palliative care and advance care planning. One stated,

> *‘If you’re better informed, you’ll be able to make a better decision’*; whilst another said, *‘it would have to be a wider thing, it’s about getting information and also* [getting] *it in a way that* [people] *understand’*.

Participants also spoke about the need to use social media and its role as a global information resource. Many agreed that such online platforms were better able to reach younger generations, but some cautioned being able to trust 'everything you see online', indicating that some regulation would be required to ensure that the information people were searching for was accurate.

There was an overarching feeling that this information and need to educate people was ultimately about 'supporting them' to make informed choices and decisions about their lives and their death. Some discussed how this could be achieved by improving healthcare professionals' understanding and awareness of palliative care and advance care planning. The idea of a 'holistic' approach to patient's palliative care symptoms/needs was highlighted and how constraints in the current healthcare system (including time restrictions on appointments and limited funding in terms of resources) aggravate healthcare professionals' difficulty in prioritising patient's needs (their emotional and psychological needs with their physical medical needs). One participant stated,

> *'I think all nursing is a vocation and I think, I'm sure it must be so difficult for some of the nurses who are trying to deal with it, because they're so busy trying to deal with the medical side of it… they just don't have time to do it [emotional support]'.* (PCACPI007)

Normalisation

Several participants agreed that it is important that we normalise the idea of advance care planning and palliative care to encourage them to be part of everyday language. There was a sense amongst the participants that introducing these conversations informally within families and amongst peers (for e.g. in church or social groups) was the best way to break down barriers and 'taboo' that exists surrounding death and planning for death. Many also highlighted that these conversations should be happening at a much earlier stage and that parents should be including children in these conversations. One participant stated,

> '*…So I think the best way of doing advanced planning is for people to have thought about it and discussed it at a much earlier stage…it's just a discussion,*

> *just as you would discuss getting a job, which you do with children…'* (PCACPI004).

Participants also discussed the need to recognise that younger people get sick and need to be aware of advance care planning options as well. One mentioned that advance care planning and topics like organ donation could easily be broached at school, and children could be introduced to the terminology and have the opportunity to share their experiences and concerns with other members of their peer groups. One suggested,

> '…*the solution is that people should be taught about advanced care planning at school level. So that you're actually thinking about advance care planning and it's part of the curriculum and lessons, so that when your mum or dad come to have to have something, you're got an awareness instead of it just hitting you like a brick wall and you know, when you come to have your care, it means that your children will be able to support you through that…'* (PCACPI002).

CONCLUSIONS & RECOMMENDATIONS

With an ever-growing ageing population across the world, with complex chronic conditions; the need for palliative care research is vital in order to address changing needs, create robust palliative care services and enhance patient care and experience (35). At a global, national and regional level, there has been a concerted effort to better understand the role of palliative care and advance care planning. However, previous evidence has documented a lack of knowledge of palliative care and advance care planning amongst the general public. A concern reiterated by the findings from this research that outlined huge variances amongst individuals regarding their knowledge of the concept of palliative care and the idea of advance care planning. This is the first regional study in Northern Ireland that has explored the public's level of awareness, knowledge and views relating to palliative care and advance care planning.

Knowledge and Awareness of Palliative Care

Overall, the results demonstrated a lack of awareness and knowledge. Although two in five participants had experience of palliative care through a friend or relative, only one in five (22.6%) were able to accurately define the term palliative care (answered all 13 PaCKs items correctly). Similarly, only one in four participants (28.5%) acknowledged an understanding of the term advance care planning, with only 2% having an advance care plan already in place. Results from the quantitative element of this project highlighted that factors such as gender and education impact on knowledge of palliative care. Moreover, those from rural communities scored higher in terms of their knowledge of palliative care and this may be linked to the support networks that exist in more rural areas and the community cohesion at times of distress.

Advance Care Planning

Over 80% of participants acknowledged the benefit of advance care planning (give them comfort and a sense of control), however there was a disconnect with 60% of participants having no interest in finding out any more about advance care planning. This raises questions about who, where, how and when to consider some of the aspects related to advance care planning. However, interestingly the findings also reveal a positive trend in terms of the public's attitudes toward advance care planning from earlier research in the area (36), with the Northern Irish population also showing little concern when it comes to the worries commonly associated with advance care planning; only 16.7% were worried about their wishes not being respected, similarly only 20.2% were worried that advance care planning would mean that they would be unable to change mind about their advance care plans. However, a major barrier to advance care planning remains around initiating such conversations, with participants acknowledging that they are more likely to have informal discussions with family/friends (60%) versus more formal discussions with healthcare professionals, including the GP (40%); nurse 22.7%; and social worker (16.7%). Similar trends reporting confusion and misunderstanding surrounding the role of advance care planning have been noted in the literature (37–39).

Misperceptions of Palliative Care

Previous studies by Collins et al (21) found similar gaps in knowledge and misperceptions of palliative care and the increasing evidence indicates what could be considered as an 'image/language problem' for palliative care. The qualitative findings from this study added additional insight to this lack of knowledge and misperceptions. Some of the respondents acknowledged the complexity and specialism of palliative care and many used their own personal experiences of end of life care with family and friends to interpret their understanding of palliative care and advance care planning. However, their accounts highlighted a sporadic understanding of the terms, with respondents recognising the terminology but being unable to articulate their meaning. These findings are similar to previous literature on public awareness of palliative care and advance care planning (17,23,40,41). Moreover, current understanding was intrinsically linked to personal experiences, good or bad. Without formal guidance, such experiences provided a framework upon which to articulate and base their understandings.

These key misperceptions of palliative care need to be addressed and speak to the need for a public education programme, seeking to address key knowledge gaps. Health education is "any combination of learning experiences designed to help individuals and communities improve their health, by increasing their knowledge or influencing their attitudes" (42).. In 2004, the WHO advocated for public health policies to include public health education to increase awareness of palliative care using a variety of media and within a range of communities (2). Therefore, it is vital to consider some essential components of the educational intervention as a range of approaches may be appropriate. Building on the work of Collins (21), the increasing evidence base, and drawing from aspects of the PaCKS tool, some of the following essential components of educational message are proposed (see table 5).

Table 5 – Essential Components of Educational Message for Palliative Care

Essential Components
Palliative care considered as a system of ‘best care’, not linked to specific ‘place’ or setting
Viewed as an active approach to care, offering solutions and improving quality of life
Enabling people to stay out of hospital and provided across all settings, all conditions and all times.
Enabling choices, decision making and facilitating goals of care for both patients and families
Providing expert management of symptoms from members of specialist and generalist multidisciplinary team
Facilitation of living independently as well as possible for as long as possible
Earlier integration in the patients’ journey and includes but not just focused on end of life care.

In addition, the message needs to be accurate and from trusted sources; include both voice of patient /carer alongside health professionals; general and yet also including tailored information to specific needs of groups, for example gender; age and rural versus urban communities; taking cognisance of media and methods of media communication.

In conclusion, findings indicate a dearth of awareness, lack of knowledge, and misperceptions among the Northern Ireland general population regarding palliative care and advance care planning. Despite this, however, palliative care and advance care planning were recognised as important and a range of strategies to enhance understanding and engagement were offered including the need for education and publicity. With a growing ageing population, and the improvements in the range of palliative care services since the publication of the Living Matters; Dying Matters: A Palliative and End of Life Care Strategy for Adults in NI in 2010 (32), an increase in awareness is needed to improve knowledge of and access to services, empowering individuals, communities and society. Doing so will help to ensure Northern Ireland realises the national and international objectives of palliative care.

Based on the objectives and research findings, the following recommendations are outlined.

Objective 1: Awareness, knowledge, and views about palliative care and advance care planning among the public

- There is a need to increase public views and knowledge of palliative care across the life span and different age groups. Increasing awareness and understanding of palliative care, both among the wider public and health and social care professionals, is crucial to opening up discussion about death and dying and encouraging people to think about and understand the role of palliative care in supporting people living with life-limiting conditions.

- Key misperceptions are still prevalent across Northern Ireland. To address this requires agreement on the key components of the message for palliative care, shared terminology and consistency in delivery. Such an approach would enable a potential ‘reframing’ of palliative care, aligned to key messaging.

Objective 2: Influencing factors in the provision of palliative care and advance care planning and best practice

- Palliative care is still viewed as care of patients with cancer in the last six months of life. Efforts should be made to integrate palliative care and advance care planning into bigger public health campaigns on healthy ageing as part of everyday conversations, instead of waiting for a diagnosis of a terminal illness.

- Funding and resource planning is required to support the early integration of palliative care and advance care planning.

- Young adults, men, and people not born in the UK showed lesser understanding of advance care planning and palliative care. Public health campaigns should target these groups and tailor information and delivery to match their needs.

- Concerns of “fake news” highlight the importance of trustworthy, credible sources being involved in the coproduction and delivery of materials.

Objective 3: Behaviour among the public regarding holding discussion and making advance care plans

- The general public acknowledge the importance of planning ahead and have willingness to participate in principle. However further refinement and consideration required for when this applies to a person on an individual basis. This indicates the need to develop a targeted approach addressing personal and individual considerations alongside indicating benefits and allaying concerns.

- Specific strategies need to be considered around how initiatives related to advance care planning are progressed. Some suggestions include the use of targeting other institutions outside of the health care system, for example workplaces, financial advisors and solicitors. Other examples include:
    - Work with film and media outlets to weave palliative care and advance care planning into the storyline of popular shows to help break down views of them as taboo.
    - Adapt educational materials for a younger audience and start conversations in schools and universities.

Objective 4: Strategies to raise awareness within a public health framework.

- There is a need for wider understanding and policies that enable support for palliative care and advance care planning implementation as not just the remit for health and social care. A public health approach to palliative care needs support and wider engagement and co-operation across a range of stakeholders. These include for example, individuals, community groups, health and social care professionals, the education sector, voluntary sector, local and central government, employers, and faith groups.

- Education and information are critical to understanding what palliative care is and how it can help improve quality of life, support future planning, and help people to live well until they die.
  - Education and information targeting the general public should include both general information provided at a universal level, tackling the misconceptions, but also include tailored information targeted at different groups in society to enhance awareness of palliative care and advance care planning. Such tailored groups may include consideration of urban and rural populations, different age groups, and gendered nuances.
  - Education and information targeting healthcare professionals regarding the initiation of advance care planning discussions should be focused earlier in the disease trajectory. There is a need to reinforce the message that health and social care professionals have a role to play in helping people understand the many aspects of palliative care including its psychological, emotional, spiritual, social and physiological benefits.
  - Display promotional materials on palliative care and advance care planning in public places within the health and social care sector.
- Despite palliative care and advance care planning being recognised as a significant policy priority, further research is required to examine the impact of initiatives among the public's understanding.
- Key strategies need addressed, and exemplars of good practice outlined that illustrate how community support can be developed and maintained.

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APPENDICES

Appendix 1

Table 1 – Range of Demographic Characteristics of Participants to the Survey

	Category	Number (Percentage)
Gender	Male	501 (41.7%)
	Female	700 (58.3%)
Age	18-24	87 (7.3)
	25-34	174 (14.6%)
	35-44	203 (17.1)
	45-54	210 (17.7%)
	55-64	189 (15.9)
	65-74	173 (14.6%)
	75-84	121 (10.2%)
	85+	31 (2.6%)
Marital Status	Single	378 (31.8%)
	Married	514 (43.3%)
	Married but separated	57 (4.8%)
	Divorced	103 (8.7%)
	Widowed	136 (11.4%)
	No answer/Refused	13 (1.1%)
Description of Area Lived	Big City	212 (17.7%)
	Suburbs/Outskirts of big city	109 (9.1%)
	Small City or Town	498 (41.5%)
	Country Village	172 (14.3%)
	Farm or Home in Country	210 (17.5%)
Household Income	Fallen behind prices	591 (49.2%)
	Kept up with prices	473 (39.4%)
	Gone up by more than prices	52 (4.3%)
	Don't Know	85 (7.1%)
Country of Birth	Northern Ireland	1011 (84.2%)
	England/Scotland/Wales	72 (6%)
	Republic of Ireland	33 (2.7%)
	Elsewhere	85 (7.1%)
Ethnic Group	White	1147 (95.5%)
	Other	54 (4.5%)
Highest Qualification	Degree or higher	302 (25.3%)
	Diploma or equivalent	98 (8.2%)

	GCE A Level or equivalent	151 (12.7%)
	GCSE (A-C) or equivalent	223 (18.7%)
	GCSE (D-G) or equivalent	124 (10.4%)
	No qualifications	295 (24.7%)
	No answer/Refused	8 (.7%)
Religion	Catholic	431 (38.2%)
	Protestant	496 (43.9%)
	No Religion	202 (17.9%)
	Missing/Other Religion	72 (6%)