

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

## **Evidence Brief**

### Why did we start?

The need to raise awareness and understanding of palliative care and advance care planning (ACP) amongst the public, within a public health approach, has been recognised as a key policy priority, internationally, nationally, and regionally. The research aimed to explore the awareness, knowledge and public views and behaviour in relation to palliative care and ACP and identify strategies to raise awareness within a public health framework.

### What did we do?

A two phase, sequential mixed methods design was utilised, including a cross-sectional survey (n=1,201) and qualitative interviews (n=19)/focus groups (n=2) with members of the public. The first phase assessed the knowledge, attitudes and behaviours of the public in Northern Ireland regarding palliative care and ACP, and the second phase explored these concepts in depth to give meaning to the numerical data and identify future strategies for public promotion of palliative care and ACP.

### What answer did we get?

Findings indicate a dearth of awareness, lack of knowledge, and misperceptions among the general population regarding palliative care and ACP. Almost half of survey respondents had some direct experience of palliative care, however, only one in five had a completely accurate understanding of the term. Variances in understanding were associated with several demographic characteristics however reasons why these are influencers is unknown. Understanding is derived from limited ad hoc personal experiences focusing on the end of life and not the holistic palliative care journey. Palliative care is recognised as a “taboo” subject, therefore, it was recommended to weave conversations into everyday platforms, such as TV soap storylines. Less than a third of respondents recognised the term “ACP” and only 7% had engaged in a conversation. Friends/family, the General Practitioner or a member of the clergy were most likely approached to discuss the topic, and Google was a key source of information. ACP was recognized as important despite limited awareness, lack of knowledge and misperceptions. Whilst the public report a willingness to engage in such conversations, societal restrictions impinged on this occurring. Despite this, however, palliative care and ACP were recognised as important and a range of strategies to enhance understanding and engagement were offered including education and publicity.

### What should be done now?

By waiting until a medical emergency arises, it hinders normalisation of the early conversations advocated in public health policy. By shifting the view of palliative care to earlier integration across disease types and care settings, and ACP as a “normal” conversation to have irrespective of health status, essential conversations can start earlier and ensure appropriate care reaches everyone who would benefit. A community action approach to enhance understanding and engagement was supported, however, a ‘one size fits all’ approach will not work; rather bespoke targeting is required with educational and media messaging aligned. There is a need for public health campaigns to recognise the disparity in what palliative care is seen to offer (end of life care), and move forward by raising awareness, removing misconceptions, and increasing openness to holistic palliative care. A consistent message from a trustworthy source, inclusive of the voice of the patient, carer, and healthcare professional, and offering both general and tailored information to the needs of specific groups is advocated.

## **BACKGROUND**

Palliative care is 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). 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 (2). The World Health Organisation (WHO) (3) advocate that palliative care should be considered as a public health issue, with access to such care considered a human right (4,5). 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 (6). Despite this recommendation, evidence repeatedly demonstrates that palliative care is accessed late in the illness course (7). What the public know and understand about palliative care may impact on future access to quality care in the event of a serious illness (8). However, international research suggests that palliative care is poorly understood among the general public and misperceptions continue to exist.

Advance care planning (ACP), is a process that enables adults at any stage or health status to understand, identify and share their personal goals, values and preferences regarding future medical care. In the UK, advance care plans can be formal (for example, advance decisions or assigning a lasting power of attorney) or informal (advance statements regarding what the person considers important to their health and care)(9). Despite being recognised by patients and families as a difficult topic for discussion, emerging evidence pre and during COVID-19 suggests that the public might be willing to engage in ACP conversations (10,11). It helps to ensure the medical care delivered is consistent to the person's wishes/values and preferences, reduces decision-making burden, and helps families prepare for and cope with bereavement (12). However, ACP research has continually focused on older patients or in the context of a medical crisis (13–15), and evidence suggests uptake is low across the United States (16), Europe (17,18), and the United Kingdom (19,20). There is increasing recognition that ACP should engage the public outside of a medical setting, however, research would suggest there are wider societal factors which may limit patient and wider community access to ACP and 'early' palliative care. Therefore, this need to raise awareness and understanding of palliative care and ACP amongst the public, within a public health approach, has been recognised as a key policy priority, internationally (21–24), nationally (25,26), and regionally (27,28).

## **AIM AND OBJECTIVES**

The research aimed to explore the awareness, knowledge and public views and behaviour in relation to palliative care and ACP and identify strategies to raise awareness within a public health framework. The objectives of the research were to identify:

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

## **METHODOLOGY**

Design: A two phase, sequential mixed methods design (29) was utilised, including a cross-sectional survey and qualitative interviews/focus groups. Phase one assessed the knowledge, attitudes and behaviours of the public in Northern Ireland regarding palliative care and ACP, and phase two explored these concepts in depth to give meaning to the numerical data and identify future strategies for public promotion of palliative care and ACP.

Participants: Survey respondents included a random representative sample of adults from the Northern Ireland population aged 18 years and over; selected from a database of addresses. Participation was voluntary. Following completion of the survey, respondents were asked if they would like to participate in a second, qualitative phase. Those who agreed had their contact information collated (separately to survey responses). Willing participants were contacted via telephone. Inclusion criteria included age 18-80 years; able to speak and read English; had previously completed the survey and were willing to participate, able to provide informed consent; and not recently bereaved (last six months). Eligible participants were sent study information and upon receipt of the consent form, were invited to take part in a one-off focus group or interview.

Data Collection: Phase one data were collected in 2018, as part of the annual cross-sectional attitudinal survey undertaken in Northern Ireland, known as the Northern Ireland Life and Times survey (NILT). Face-to-face questionnaires were carried out using computer assisted personal interviewing, and there was a further self-completion questionnaire which respondents were asked to fill in on a tablet, or on paper. Phase two were collected from October 2018 to July 2019 by DM, KC, EB and SMcC (postdoctoral researchers and/or specialist practitioners). The researcher was not known to participants prior to the data collection. Data were collected in a neutral public place, the participant's home, or via telephone, and were audio recorded and field notes taken.

Data collection tools: Data collection tools were piloted with academics and NILT data collectors prior to implementation. The palliative care section of the survey was based on the Palliative Care Knowledge Scale (PaCKS), a 13 item, true/false format instrument. Eight items relating to participants' attitudes towards ACP were informed by European Association of Palliative Care White Paper on ACP 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 ACP, as well as a question allowing respondents to detail with whom they had previously discussed ACP (9 options). Sociodemographic characteristics were also collected. In phase two, the qualitative interview schedule comprised broad topic areas related to palliative care/ACP, which included knowledge; knowledge and information seeking behaviours; perceived accessibility of services, and future strategies for promoting public awareness.

Data Analysis: In phase one, the number of correct responses were tallied, and scores ranged from 0 (lowest knowledge) to 13 (highest knowledge). "I don't know"/ "Not sure" responses were coded as incorrect when calculating total scores. All survey data were analysed in SPSS v 25.0. Descriptive statistics were used to summarise the participants' demographic factors and other variables. A factor analysis was undertaken on PaCKS and the factor structure was found to be acceptable. Linear regression was used to identify demographic variables that impacted on the PaCKS score and explored further using inferential statistics. Further analyses were undertaken on appropriate variables; t Tests were conducted to compare PaCKS scores across gender. An analysis of variance (ANOVA) was conducted to analyse how age, country of birth, marital status, household income, and qualifications performed on the PaCKS. Phase two data were stored and managed through NVivo Software v13. Qualitative data were transcribed and anonymised. Transcripts were analysed using thematic analysis (30) which involved a six-step process: familiarisation, generating codes, searching for themes, reviewing themes, defining and naming themes, and producing a report. Themes were derived by exploring patterns, similarities and differences within and across the data. Data analysis was done by two researchers (OB and LH-T) and discussed with a third (FH) to enhance credibility and trustworthiness.

Integration: Integration was evident through data transformation between phase one and two and merging in the results and discussion. The data from phase one informed the development of the interview schedule utilised in phase two, and the results from both phases were analysed in parallel, integrated using data matrix and weaving the thread techniques, and presented thematically throughout the results and discussion.

## **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 AllHPC, 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**

Description of the sample: A total of 2,161 people were contacted, 1,201 of whom completed the survey (response rate 56%), representative of the demographic profile in NI. The respondents were aged between 18 and 95 years (mean: 61yrs). The largest proportion of the population, 17.7% (n=210) were aged between 45-54years. Over half were female (58.3% n=700); most were white (95.5% n=1147) and born in Northern Ireland (84.2% n=1011). Over two fifths were married (43.3% n=514), lived in a 'small city or town' (41.5% n=498) and in terms of religion identified themselves as protestant (43.9% n=496). Over a quarter (25.3% n=302) indicated that they had a degree or higher qualification, and just under a quarter (24.7% n=295) reported no formal qualifications. A quarter of respondents (25.6% n=307) reported a physical or mental condition or illness that had lasted or was expected to last more than 12 months. Of those respondents, 58% (n=178) indicated that the condition/illness reduced their ability to carry out day-to-day activities a lot. Only 8.1% (n=97) of respondents indicated that they had someone living with them, for whom they had a caring responsibility. A further 9.6% (n=115) had a caring responsibility for a sick, disabled or elderly relative or friend not living with them. Twenty-five participants took part in phase two. Almost all respondents (96%) were white; 60% were male and nearly three quarters (72%) were married or co-habiting. Less than a quarter (24%) of those who participated were under 50 years, with the largest proportion of respondents (36%) aged between 61-70 years. Almost half (48%) were retired, and all were Christian.

Prior Knowledge of Palliative Care: Almost half of survey respondents (44.6%) had some direct experience of palliative care through a friend/relative. Approximately one in ten (11.2%) had a job that involved working with people who received palliative care and three respondents (0.3%) were receiving palliative care. A fifth of respondents (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. Only 14.2% of respondents indicated that they had no prior knowledge of the term palliative care. It was clear from the qualitative findings that respondents' knowledge and understanding were largely attributed to personal experience. Many described their experience of palliative care as end of life care which was "*traumatic*" or as having "*happened very fast*" in which learning occurred in an ad-hoc sporadic manner. Several respondents focused on medication in the final stages of death and resuscitation options, highlighting "*a good death*" and "*dying comfortably*" as the optimum goals.

Variable Understanding of Palliative Care: Overall, 22.6% of respondents 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. The

mean PaCKS score was 8.31 (standard deviation=4.91, range 0-13). People who scored highly on knowledge questions related to palliative care were more likely to have a higher level of education and be female, married, aged 55-64, and born in Northern Ireland. The three most commonly held misconceptions included: Palliative care is exclusively for people who are in the last 6 months of life (55.4% answered incorrectly); A goal of palliative care is to address any psychological issues brought up by serious illness (42.2% answered incorrectly); and a goal of palliative care is to improve a person's ability to participate in daily activities (39.6% answered incorrectly). Respondents in the qualitative phase noted that palliative care happened "*at the very end*" when there was "*no hope*", or "*no other treatments*" available. Most respondents agreed that palliative care involved different healthcare professionals but most struggled with clarifying the range of support available.

Shortcomings in current palliative care information and provision: Some respondents in phase two discussed how improvements in healthcare professionals' understanding and awareness of palliative care could facilitate a more 'holistic' approach to patient's palliative care symptoms/needs. However, constraints in the current healthcare system exacerbate healthcare professionals' difficulty in prioritising patient's emotional and psychological needs alongside physical and medical needs:

*"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)

Informing people about palliative care involves facilitating individuals to realise and acknowledge their own mortality. One respondent noted that palliative care could be included in something like life insurance, that way, people availed of it (and learned about the benefits) in the context of living and paying for their mortgage but knowing that they'd be taken care of in the future.

Promoting public awareness of palliative care: Many respondents acknowledged the "*taboo*" that still exists around public discussions about death and dying, and that in some instances it can be very difficult to broach the subject, even with family and friends:

*"It's never talked about to be quite honest...like deaths and funerals – nobody likes to envisage the end..."*. (PCACPI003)

Many respondents who were interviewed openly acknowledged that their religious or cultural beliefs dictated the decisions they make in terms of their care, both physical and spiritual, and were largely unconcerned with the idea of doing something different/contrary to what they were familiar with. A number of respondents also highlighted the limitations of human knowledge:

*"...there is no point in worrying about what was going to happen. If it's going to happen anyway..."* (PCACPI002).

Future strategies to improve understanding of palliative care: Respondents suggested dissemination of information via a variety of platforms. More traditional methods discussed included information in GP surgeries, libraries, posting leaflets, and traditional media platforms, alongside the use of media and television such as soap storylines. 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 was accurate. There was an overarching feeling that this information and the need to educate people was ultimately about "*supporting them*" to make informed choices and decisions if that was their wish.

Knowledge of ACP ("A last resort"): 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.

Friends/family (60.6%, n=40), the General Practitioner (GP) (43.9%, n=29) and a member of the clergy (31.8%, n=21) were most likely approached to discuss the topic by those who reported that they had engaged in conversations, and in many cases multiple people were approached. "Asking google" was another source of information, however, respondents sometimes worried about the credibility of online information. ACP 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.

*'...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)

Phase two respondents noted ACP was focused on funeral wishes and medical care/treatment options once a terminal illness had been diagnosed.

Attitudes to ACP ("It's inevitable but you don't talk about it"): Almost two thirds (63.3%) of respondents felt they were in good health and did not want to think about ACP. However, 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 followed. All respondents were asked if they would like to find out more about ACP and almost two thirds (68.3%) said no. None of the respondents who took part within the qualitative phase had put an advance care plan in place. Whilst some had started to think about future care, most found the subject difficult to broach with loved ones or HCPs. Some acknowledged that introducing the topic among family and friends could be perceived as an indication of an impending problem or viewed as depressing. Respondents felt ACP was for those who were older or for when a "health crisis is looming". Generational differences were also noted, with a belief that older people may be more able to acknowledge their mortality, whilst younger generations felt it wouldn't "affect them". There was a recognition that such attitudes can be challenging, and respondents suggested a more tailored educational approach should be offered for different generations. Respondents also acknowledged that having a shared experience (being directly affected) often facilitated discussions:

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

Future strategies to promote ACP ("If you're better informed, you'll make a better decision"): Whilst ACP was viewed as an "individual responsibility", respondents noted the need for government leadership to aid its implementation into everyday life. Integrating ACP into existing events such as applying for life insurance schemes could stimulate family discussions on the subject. Yet, respondents recognized a dearth of standardized lay information hampered public engagement. They recommended that information should be tailored to convey positivity such as the concept of a "a good death" and dying in a "good way", and broached with everyone, irrespective of their age or health status. Disseminating such information could be done through information in GP surgeries, libraries, posting leaflets, and regionally incorporating media platforms. There was some discussion about the benefit of using social media platforms and weaving the topics into soap storylines, as a way stimulating discussions that will ultimately sensitize people:

*"If you're better informed, you'll be able to make a better decision".*

Normalizing the conversation as part of everyday language was key for several respondents. Introducing these conversations informally within families and amongst peers (for example in church or social groups) was seen as the best way to break down existing barriers. They suggested including ACP information within the school curriculum:

*"...people should be taught about ACP at school...so that when your mum or dad come to have something, you've got an awareness instead of it just hitting you like a brick wall"* (PCACPI002).

## CONCLUSIONS

This regional study in Northern Ireland explored the public's level of awareness, knowledge and views relating to palliative care and ACP. Findings indicate a dearth of awareness, lack of knowledge, and misperceptions among the general population. Despite this, however, palliative care and ACP 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 (31), 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.

Palliative Care: Overall, the results demonstrated a lack of awareness and knowledge. Although two in five respondents 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). Factors such as gender, age, and education impact on knowledge of palliative care, however, it is unclear why such disparities exist and the impact of these on palliative care receptivity. Personal experience shaped many respondents' views on palliative care and potentially their misconceptions; the most common misconception being that palliative care is exclusively for people in the last six months of life. Despite respondents advocating the need to hold open conversations about palliative care in society, they had concerns about the social taboo of talking about death and fear of causing upset. There is a need for public health campaigns to recognise the disparity in what palliative care is seen to offer (end of life care), from the public's perspective, and move forward by raising awareness, removing misconceptions, and increasing openness to holistic palliative care. To address misconceptions and knowledge gaps, a consistent message from a trustworthy source, inclusive of the voice of the patient, carer, and healthcare professional, and offering both general and tailored information to the needs of specific groups is advocated. It is also vital to consider some essential messages of the educational intervention:

- Palliative care is 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 not *just* focused on end of life care.

Advance Care Planning: One in four respondents (28.5%) acknowledged an understanding of the term ACP, with only 2% having an advance care plan already in place. Almost two thirds (63.3%) felt they were in good health and did not want to think about ACP. This raises questions about who, where, how and when to consider some of the aspects related to ACP. Misconceptions resulting from a lack of public education, lack of exposure to the topic, and personal experience of family and friends at the end of life have resulted in ACP being viewed medically and associated with end of life care, which may explain why the majority of respondents did not want to receive more information. A major barrier to ACP in this study

was initiating such conversations, with respondents acknowledging that they are more likely to have informal discussions with family/friends versus more formal discussions with healthcare professionals. By waiting until a medical emergency arises, the emotive context may impact on the clinical and legal decisions made (32), and this approach hinders normalisation of the early conversations advocated in public health policy (33). In this study, respondents identified opportunities to provide thinking space and facilitate conversations outside of an end of life situation. For example, integrating ACP into life insurance policy, story lines in television programmes and informal sessions in local community groups. Family opinions also play a key role in the willingness to engage in both palliative care and ACP discussions; respondents in the current study noted that they would trust their family members to follow their wishes. Therefore, further research should consider a focus on the role of the family and provide them with the knowledge and skills to initiate, and support a loved one through, ACP discussions.

## **PRACTICE AND POLICY IMPLICATIONS/RECOMMENDATIONS**

### Awareness, knowledge, and views about palliative care and ACP among the public

- Increasing awareness and understanding, both among the wider public and health and social care professionals, is crucial to opening up discussions
- To address key misperceptions requires agreement on the key components of the message for palliative care, shared terminology and consistency in delivery.

### Influencing factors in the provision of palliative care and ACP and best practice

- Efforts should be made to integrate palliative care and ACP into bigger public health campaigns on healthy ageing as part of everyday conversations.
- Funding and resource planning is required to support early integration.
- Young adults, men, and people not born in the UK showed lesser understanding of ACP 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.

### Public behaviours regarding discussing and making advance care plans

- There is a need to develop a targeted approach addressing personal considerations to holding ACP discussions alongside indicating benefits and allaying concerns.
- Specific strategies need to be considered around how initiatives related to ACP are progressed. For example, target institutions outside of healthcare system, work with film and media outlets, and adapt educational materials for a younger audience.

### 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 ACP implementation as not just the remit for health and social care.
- Education and information targeting the general public should include both general information tackling the misconceptions, but also include tailored information targeted at different groups in society to enhance awareness.
- Education and information targeting healthcare professionals' discussions should be focused earlier in the disease trajectory, focused on the psychological, emotional, spiritual, social and physiological benefits.
- Further research is required to examine the impact of initiatives on 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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