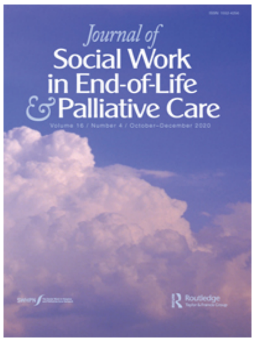

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The Heart of Living and Dying: Upstreaming Advance Care Planning into Community Conversations in the Public Domain in Northern Ireland.

Deirdre Mc Kenna[a], Johanna O'Shea[b], and Liz Tanner[c]

[a]Southern Health and Social Care Trust, Craigavon, Northern Ireland; [b]Applied Social Sciences, Social Work Department, Maynooth University, Co. Kildare, Ireland; [c]Social Work Training Unit, Southern Health and Social Care Trust, Armagh, Northern Ireland

ABSTRACT

This paper provides an evaluation of the Heart of Living and Dying (HLD) Initiative. This initiative is a group process that attempts to bring Advance Care Planning (ACP) into the public domain. It encourages participants to consider what matters to them in their living along with their hopes, preferences, and wishes for their final years and end-of-life care. An inductive, interpretive, and naturalistic approach allowed the researcher to study these phenomena in their natural setting i.e., the community. This qualitative study used 5 focus groups with 17 people and employed thematic data analysis to identify key themes. All participants in the HLD speak from a personal perspective irrespective of any professional background. It transpired that 16 respondents worked in health and social care, which subsequently became noteworthy in the findings. Three key themes were identified: (a) feeling emotionally safe enough to have such sensitive conversations is vital; (b) participating in the HLD process increases the confidence of those participants who worked in health and social care, to undertake ACP conversations and (c) planning ahead is a complex, staged process rather than a single record-making event. The Covid-19 pandemic crisis reinforced the need to upstream ACP initiatives such as the HLD, as the norm for everyone, since all of us will one day die. It is recommended that the HLD be incorporated within ACP training given that the experiential nature of it and the use of groups was reported to build confidence in facilitating ACP conversations. A virtual HLD process needs to be developed to adapt to restrictions on gatherings due to Covid 19.

KEYWORDS
Advance care planning; community development; palliative care; public health approach

Introduction

The reality that one day each of us will die, is something few of us consider and fewer still, plan for or discuss. Advance Care Planning (ACP) is a process involving an ongoing discussion typically between persons with a

CONTACT Deirdre Mc Kenna ✉ deirdre.mckenna@southerntrust.hscni.net Southern Health and Social Care Trust, Craigavon, Co. Armagh, Northern Ireland

diagnosis of a serious illness, their family/carers, and their health care professionals. The discussion often focuses on the person's living, as well as their wishes and preferences for their care as they approach the end of their life. Numerous studies on family or caregivers experience of ACP have described a consensus that meaningful ACP conversations are beneficial regarding the enhanced quality of life, peace of mind, clarifying decisions, and easing carer burden (Ashton, Roe, Jack, & McClelland, 2016; Bollig, Gjengedal, & Rosland, 2016; Detering, Hancock, Reade, & Silvester, 2010; Fried, Zenoni, Iannone, O'Leary, & Fenton, 2017; Jeong, Higgins, & McMillan, 2011; Murray et al., 2016; Preston et al., 2012; Sellars et al., 2018). These studies highlighted the importance of the timing of ACP conversations. Identified gaps include health and social care professionals' understanding of the ACP process and the importance of clear communication.

In 2015, the All-Ireland Institute of Hospice & Palliative Care survey "Let's Talk" reported that 68% of people said their greatest concern is planning for their future. Kellehear (2013) suggested that a prevalent culture exists that keeps discussions relating to death, dying loss, and care out of the public domain. Public health approaches to Advance Care planning look to communities and social networks to normalize conversations by providing platforms that both inform and enable open discussion. The Heart of Living and Dying (HLD) initiative is a social model that looks at people within the context of their own social networks and opens the discussion in communities where people live, die, and grieve, thus bringing Advance Care Planning into the public domain. By upstreaming ACP into conversations in communities with the general public, as a public health initiative, participants are more likely to be in good health and may therefore feel safer discussing their wishes, preferences, or goals of care because they may feel their own death is a long way off.

HLD is a two-hour group process where members of the public are invited to participate in a supported conversation at a local community venue about what matters to them in their living and dying and to begin to plan ahead. This public health initiative was developed in response to the researcher's practice experience of the need to offer opportunities for ACP to the general public before the onset of serious illness. The session has a lead facilitator with overall responsibility. The process moves between the whole group and small group conversations. An additional staff member sits in each of the small groups and acts as a conversation guide and support to group members if they become distressed. Prompt questions are offered to help stimulate discussion. A visual artist is also in attendance whose role is to "listen" to what is being shared and then create an art piece that is sent to participants as a keepsake of the event. Publicity is posted on social media, in doctors' surgeries, pharmacies, libraries, community groups, church bulletins, and local newspapers. This upstreaming of ACP, according to Prince-Paul and DiFranco (2017), could potentially transform culture and ensure more people have their wishes and preferences honored at end of life. It also aligns with Kellehear's (2013) assertion "*that to achieve optimal health and wellbeing in the 21st century a community engagement approach to health must extend its active concern to the end-of-life itself*" (p. 1074). Biondo et al. (2019) concluded that groups in the community are both "well placed and keen to help promote ACP beyond the healthcare system" (p. 10). Furthermore, Litzelman, Cottingham, Griffin, Inui, and Ivy (2016) asserted the foundation for normalizing discussions such as ACP is through community organizations. This study aims to examine evidence of the effectiveness that the HLD offers to do just that.

Methods

Study design

This study was located in the general paradigm of qualitative methods given the focus on an exploration of people's hope, fears, and wishes about their death and dying and their experience and views on the timing of ACP conversations. An inductive, interpretive, and naturalistic approach (Lincoln & Guba, 1985) allowed the study of these phenomena in their natural setting i.e., the community. Qualitative methods were the optimal choice to build new insight and knowledge (Ulin et al., 2005) directly from the participant (Richie et al., 2013) around this area, therefore social work core values of service user involvement and self-determination are honored.

Method

In total 17 people participated in 5 focus groups in April and May 2019. Focus groups encourage creativity and responsivity from group members stimulating spontaneity of expression and social interaction (Engel & Schutt 2016), and reflect what Stewart and Shamdasani (2014) see as the production of rich understandings. They offer 'expert by experience' group participation, encouraging collective ownership and control of the discussion topic (MacNaghten & Myers, 2004). Focus groups were considered more appropriate than interviews to reduce bias given that the HLD initiative was written and facilitated by the researcher and, as such, individual interviews conducted by the researcher could unduly influence interviewees (see Kamberelis & Dimitriadis, 2013).

Recruitment and sampling

A combination of purposive and quota sampling was used to recruit participants. A letter was sent to all those who had participated in a Heart of Living and Dying conversation, advising them of the study and inviting them to indicate their willingness to participate. Inclusion criteria were individuals who had participated in the HLD group conversation; self-selected and opted into the research and were available to attend a group. The focus groups took place in accessible, comfortable, and discreet community venues, which was considered integral to undertaking qualitative inquiry to allow rich and meaningful conversations to take place.

Data collection

Each focus group lasted approximately one hour and, with the informed consent of the participants, was audio-recorded, transcribed verbatim, and anonymized. The researcher also took notes during the focus group. An interview guide (Stewart & Shamdasani, 2014) was developed by the researcher in conjunction with a service user advisor and based on core themes identified from the literature review. This guide, which was piloted on two occasions, was sufficiently flexible to enable the researcher to diverge and delve deeper into participant responses at times. This ensured a more authentic, inductive, and naturalistic approach (Lincoln & Guba, 1985) to capturing that which held particular meaning for participants.

Data analysis

Braun and Clarke (2006) thematic analysis approach was adopted, which allowed the researcher to glean any potential patterns of meaning emerging and to test these across the data. NVivo software was used to manage the large volume of data and to categorize codes and themes. In line with a qualitative inquiry, the researcher identified dominant and subordinate themes by moving data between codes and listening over and over to the original transcripts to stay ‘true’ to the data. This measured approach ensured greater integrity and rigor in the analysis (Nowell, Norris, & White, 2017).

To further improve rigor and minimize the risk of bias, a service user reviewed the coding and themes identified in a randomly chosen transcript. The researcher maintained a reflective approach throughout and discussed thoughts, ideas, concepts with the service user advisor. This provided a pause where assumptions were challenged, and no hasty conclusions could be drawn. Thematic saturation was achieved (see Ando, Cousins, & Young, 2014).

Ethics approval

Ethics approval for this study was granted by Ulster University at school level. Furthermore, approval and access were granted by the Southern Health and Social Care Trust in Northern Ireland.

Results

In total 17 individuals participated in five focus groups. Unintentionally, 16 of the 17 had some professional experience of Advance Care Planning although none had previously considered this from a personal perspective. Nine were social workers in older people's services. Three of these worked in specialist palliative care; 7 were nursing and allied health professionals from a variety of adult services and there was one layperson. Fifteen respondents were women, two were men and all 17 were white Irish. These results, therefore, need to be understood in this context although there is no notable difference in the findings across the respondents. Three main themes emerged namely (a) feeling emotionally safe enough to have such sensitive conversations is vital; (b) participating in the HLD process increases the confidence of those participants who worked in health and social care, to undertake ACP conversations; and (c) planning ahead is a complex, staged process rather than a single record-making event.

Theme 1. Ensuring Emotional Safety: This theme relates to respondents' experience of feeling safe enough within the HLD group process to engage fully.

> "to have that protected undisturbed space and time, then you were prepared to talk from your heart. Because you knew it was not going to be stamped on." Focus group (FG) 2 resp.**[N/A]L.**

Data described a range of factors that created this sense of safety including how the HLD was advertised, the venue, how participants were welcomed when they arrived, the use of small groups, skillful facilitation, the role of the Arts, and the pacing of the HLD two-hour group process.

Respondents described the small groups as respectful spaces which helped create a sense of safety, where members felt that listening to one another encouraged them to speak personally and openly about sensitive matters and where they were listened to without judgment…

> "… I definitely wouldn't have opened up as much … I wouldn't have felt able to do that and I think within our group there was no pressure" (FG 1 resp D)

The small group allowed people to pause and reflect on what was being said by others, which helped their own thinking. Respondents felt it was more comfortable than in a one-to-one situation or in an individual interview.

> "So, I think that is a big part of being safe, that you are being heard" (FG 4 resp S)

Respondents across four focus groups confirmed the need for clear information being used in publicizing the HLD to ensure that people were aware of what it was about notwithstanding that clear information may act as a deterrent for some who may feel this discussion is not yet relevant to them.

> "I know I mentioned to a lot of people would you like to come. 'ah no it's too morbid a topic I don't want to talk about it, I don't want to think about dying'" FG 2 resp. Mg

There was broad agreement that irrespective of why people came, the experience of participating was personally and professionally valuable and that the most effective means of advertising is by word of mouth.

The data indicated that skillful facilitation is vital to creating a sense of safety throughout the HLD group process. Respondents described the facilitator's competence in facilitating groups, and her confidence and comfort in discussing issues of death and dying, helped them to speak more openly and honestly about their own fears and hopes. Respondents remarked on the facilitator's high level of attentiveness to what was happening within the small groups and to the pace of the work. These indicators reassured participants that they were safe. Respondents also indicated effective interventions by the facilitator helped the person or group progress, which reassured them that support was available if they needed it, for instance, if they became distressed. This experience provided a sense of safety and allowed HLD participants to risk disclosing more of themselves.

There was evidence that the artist being present as a witness to the HLD conversations and then creating a piece of art for the participants following the sessions was significant and enhanced the participants' experience of safety and of being valued…

> "the artist as well, … that all supported that feeling of being looked after and being safe." FG 1 resp. G

The venue used for the HLD was important in creating safety. Small, discreet community venues were mentioned where participants knew they would not be interrupted…

> "it was small subtle things that people might think are insignificant that made it what it was, so it was the hospitality, the room, the sweets, the art care piece, the fact the tables were small, the great facilitation, the good mix between oral presentation a few slides and then some of the prompts" FG 3 Ge

There was mixed evidence about the session length. While some respondents considered they felt safe enough to continue the conversation for longer, others felt a two-hour session was sufficient for them to address the issues and then continue their discussion with their family and friends later.

Theme 2. Growing Professional Confidence: Each focus group included participants who were employed in Health and Social Care settings. This theme relates to how their experience of participation in the HLD could be applied to their professional practice.

Across all the focus groups, curiosity about the topic of living and dying and about the HLD itself was cited as a motivating factor to attend. Some attendees anticipated they might learn something from the HLD that could help them in their professional lives. There were a significant number of comments across the focus groups on the impact of their professional identity within the HLD. Despite the explicit publicity, respondents reported having come to learn how to have ACP conversations with their patients, clients, or service users, rather than coming to participate in a personal capacity. Comments included a sense of having an unhurried time in an uninterrupted space. Some considered this quite different from their usual work-related activity…

> “because most of your training is about how you’re doing professionally isn’t it. it is so different when you are actually faced with how I feel as a person.” FG 5: resp. S

Several respondents acknowledged that, despite their professional roles in palliative or end-of-life care, they had not taken the time to reflect on their own mortality nor complete their own ACP. A change occurred within the process, where the professionals shifted from their professional perspective to a personal participation. This allowed them to consider, and talk about, their own personal wishes, hopes, fears, and values. Some respondents indicated surprise that this occurred and contentment that it did. The data showed that participants felt a shared humanity…

> “there’s the equality really of it. The equality ye know we were all equals, there was no them no us” FG 2: resp. Mt.

There was some evidence that this shift in perspective itself provided insight for the respondents to the challenges within the lives of their patients or service users…

> “and using that exercise to think, now how can I positively use that in my work and with patients (G-yeah) who are going through circumstances that you can help them through” FG 1: resp D.

While some respondents found it difficult to make this shift initially, the data described that it was precisely this changed perspective which provided them with valuable learning, and insight, to help them in their professional lives, to have these sensitive conversations with people…

> “So, I’m really grateful for that from a personal perspective, and a professional perspective, I found it really positive and I suppose it evoked that positive meaningful change.” FG 2: resp. L

For some, the experience of participating in the HLD provided them with experience and skills which will assist them in their work. Some described having greater empathy for the service users they work with; of being able to identify more closely with them, because they themselves have reflected on what matters to them in their living and dying. Some respondents reported that their work with people would be different as a result of having participated in the HLD …

> "I would feel a little more, connected, connected in some way with that person. I would do it differently now, I would be more in tune with that person." FG 2: resp. Mt.

Respondents described gaining more insight into the importance of getting the timing of these conversations right for the people they work with. There was an acknowledgment of how task-centered professionals can be, and of a newfound realization that these kinds of conversations need to be person led.

Several respondents reported feeling more confident about having ACP type conversations with others, both personally and professionally. This increased confidence is, for some, linked to having heard peoples' stories within the HLD and the insight that, at heart, people are very similar concerning their hopes and fears …

> "This would make us feel more comfortable or braver about having these kinds of discussions and hopefully a better death for some people." FG 3: resp. Ge.

It was also noted that the power of the personal story in education and training is something that they can apply to their professional practice …

> "…. respect for everyone's story that is much more meaningful than types of coping strategies or types of reactions." FG 4: resp. B

There was explicit recognition among some respondents of the inherent difficulties for many people in discussing death and dying. Some described the potential the HLD process has for addressing this reticence or avoidance in the wider society.

Theme 3. Planning Ahead: This theme presents the data on practical and personal plans or discussions respondents engaged in, following the HLD group process. It includes any personal impact they reported on how they live their lives now. It also reports on respondents' views about the future of the HLD itself.

> "We don't want to think about it, we're happy in our living and we don't make plans for our dying and yet that day and that exercise allowed us to think about what our wishes were and how to, bring things to the fore in a less threatening way" FG 1: resp. D

Most respondents agreed that making plans is very important, and described in some detail the benefits such discussions and planning provided. The value of making concrete plans for their final years and of making these known to family members was recognized. Yet for some it wasn't the right time for them to make a written record; they felt they were too young, or it was too soon for them. The data indicated that all discussed their preferences and wishes with family or friends, suggesting the HLD process was beneficial for them.

There was evidence that some gained ideas from the HLD experience of how to begin ACP conversations with loved ones. Furthermore, the experience seemed to raise their awareness of how they choose to live their lives now. Some reported that they may focus more on quality time with family and friends …

> "And we can tell our loved ones what our hopes are what our wishes are … and then actually we can use this to live life in the way that we want as well." FG 3: resp. Ge

Some spoke of confirmation for them of the centrality of their faith, family, and friends in their lives following the experience.

> "the 3 points that nearly everybody had … faith family and friends … we are all very different, … we all had similar priorities regardless of whether you focused on death or not it even helped you refocus on your life and what we were living for" FG 2 resp. L

Some respondents spoke about the significance of considering what their legacy might be. This offered them the opportunity to live more consistently in the way they want to be remembered …

> "the thing about how you want to be remembered impacts your life now. So, this is something you can start thinking about your life now and what you want it to be filled with now … and how you would like people to remember you" FG 1: resp. G.

Respondents spoke about planning ahead for the HLD initiative itself, which as an effective group process, created sufficient emotional safety for participants to risk these important conversations. There was some consensus among respondents that the ethos and value base of the HLD should be safeguarded, and that all HLD sessions should adhere to this model.

Limitations

HLD is a new initiative developed in 2017 with a total population of <200 at the time of this study. Consequently, this sample is small. 26 respondents were scheduled to attend whereas 17 did attend one of five focus groups. The sample was drawn from communities across political, gender, age and religious identities in Northern Ireland. However, all those who participated were of white Irish origin with other ethnic groups not being represented. Given some of the different cultural sensitivities around speaking about death and dying, a more culturally diverse group may have produced different findings.

There was potential for bias in this study, as described earlier. This was mitigated by the use of focus groups rather than interviews, to minimize the facilitator's influence. Furthermore, a service user, someone who had participated in a HLD conversation, was involved as an advisor through all stages of the study. This collaboration adds some independence and rigor to the study.

Discussion

The findings offer evidence and insights into the efficacy of the HLD as a means of addressing some of the practice challenges identified in the literature.

Ensuring emotional safety

There is perhaps little surprise that the findings here indicated the importance of participants feeling safe within the HLD group process. The central role of safety in service provision is indicated throughout Health and Social Care policy and practice documents in Northern Ireland and across the UK. Safety features prominently in the Northern Ireland Social Care Council (NISCC) Standards of Conduct and Practice. In "Quality 2020," a 10-year Department of Health, Social Services, & Public Safety strategy document for Northern Ireland (2011), a working definition of quality identifies safety as one of the three pillars which underpin quality service provision.

Since Maslow's (1943) categorization of the hierarchy of needs, safety has been considered a fundamental need second only to the need for food and water. People's perception of the importance of quality of life is discussed in the literature (Detering et al., 2010; Mori et al., 2013), and although difficult to define, feeling safe may reasonably be considered vital in any exploration of what constitutes quality of life for someone.

Respondents in this study indicated feeling safe to risk self-disclosure concerning sensitive issues of their own mortality, which was essential to explore and discuss their preferences, wishes, goals, hopes, and fears. Nembhard and Edmondson (2006) reported psychological safety is vital if people are to feel free to speak up, and that such safety is achieved when they perceive no negative consequences accruing to them if they do speak. Many respondents in this study described their association between their own potential for emotional distress or feeling vulnerable, with feeling unsafe. They also suggested that, for them, being "emotional" equated to a sense of losing control. The findings indicated that feeling safe enough within the HLD to risk emotional distress, was essential. For professionals, particularly those in palliative care services, this is a useful insight. Service users, who often report feeling out of control following a diagnosis of a serious illness, need adequate time to feel safe enough to risk their own emotional distress and engage meaningfully in ACP conversations. It is of note that, as Murray et al. (2016) indicated, meaningful ACP conversations increased people's sense of having control over decisions and preferences for end-of-life care. This could also link to the issue of timing.

The findings described several factors within the HLD which enhanced feelings of safety for the respondents. These included using appropriate community venues without interruptions to the conversations. It was important that these venues were pleasant, welcoming spaces and people were intentionally welcomed in, and hospitality offered. Bollig et al. (2016), Dickinson et al. (2013), spoke of people feeling hurried, and a general sense of haste among health and social care professionals which impacted on the ability of service users to engage in meaningful ACP conversations. Adequate time is needed for people to build rapport and feel safe enough to engage with core issues of mortality, hopes, and fears regarding a life now limited and to begin planning ahead. The findings here were consistent with the literature about ensuring the timing of these conversations is right for the person concerned, and that adequate time is available for such conversations.

The role of a sufficiently competent and confident facilitator within the HLD was found here to be central in creating and ensuring a safe space for these conversations to happen. Again, these results echo findings in the literature where training and skill in facilitating ACP conversations are essential (Bollig et al., 2016; Detering et al., 2010; Fried et al., 2017; Jeong et al., 2011; Mori et al., 2013; Murray et al., 2016). Furthermore, a level of cultural competence is important for facilitating the group since, in some cultures, openly discussing dying and death without family members and a doctor present, could be considered inappropriate and might even be seen as taking away hope (see Ng, Chan, Ng, Chiam, & Lim, 2013).

All respondents described the group as a preferable context for the conversations, rather than one to one. Within the group, they reported having felt very supported by others if they became distressed, and that someone else taking a risk to speak gave them the courage to risk speaking also. This offers new insight into how safety can be created for people to engage in ACP conversations. While the potential within groups for support for an individual from other group members is recognized in the literature, (Northen & Kurland, 2001; Shulman, 1999; Steinberg, 2003), using group work is not yet on the ACP agenda as a way of facilitating these conversations. Findings from this study provide practitioners with a useful incentive to explore the use of groups in their ACP. It should also offer social workers some encouragement to apply their group work and facilitation skills to service provision.

The attention given within the HLD group process to establishing and ensuring the emotional safety of participants is found to have enabled them to risk engaging in these delicate conversations. Respondents reported that they felt more confident in tackling the subject of death and dying, even their own mortality. Attentiveness to creating safety is one of the key principles named in the draft *Operational Guidance on ACP in Northern Ireland* (forthcoming) and states that the professional offering ACP conversations should give sufficient time and attention to the work in addition to ensuring privacy and a suitably quiet venue.

Growing professional confidence

Sixteen of the 17 respondents who participated in the HLD group process worked in Health and Social Care (HSC) and reported attending in the hope of learning how to conduct ACP conversations. The findings confirmed that they felt they gained knowledge and learning which could be applied in their own practice. They also considered that gaining this learning from direct personal experience was both a challenge and a benefit to them.

Experiential learning is an effective way of teaching adult learners (Dewey 1986; Friere, 1970; Kolb 1984). Kolb (2014) described learning as a social process where the individual experiences and learns within the relationship to his or her family, community, workplace, or social environment. The HLD group setting, with a clear purpose and a focus on personal experience, enables the individual to speak and listen, reflect and expand their own personal understanding, or awareness, of what matters to them in their living and their dying. Each individual both influences, and is influenced by others in the group, to consider, confirm, or challenge deeply held beliefs, attitudes, and values about their own mortality. For some, this focused social experience provided them with confidence and a language to articulate these same, often unspoken, core aspects of that which gives meaning and substance to their lives. Several commentators, (Dickinson et al., 2013; Preston et al., 2012; Whitehead et al., 2012) identified the detrimental impact of professionals lacking either the confidence or competence to initiate and facilitate ACP conversations. It is encouraging that those respondents, working in Health and Social Care, reported feeling more confident and competent to undertake ACP following their participation in the HLD. They also reported gaining a better understanding of the skills, knowledge, and disposition necessary to conduct ACP competently. This enables greater adherence to the current operational guidance available in Northern Ireland which specifies that ACP conversations, … .

> "… should be undertaken by health and social care professionals who have appropriate communication skills to conduct the conversations with compassion and sensitivity" (Draft Operational Guidance on ACP in NI 2016).

It is precisely respondents' ability to apply their learning from the experience of participating in the HLD to their professional lives, which they reported, accounted for their growth in confidence. This study finds that it was this insight gleaned from having the conversation themselves, which allowed them to contemplate more deeply some of the challenges and enablers which may be at play in the lives of the people they serve.

As social workers, this resonates with our recognition of the importance of developing the capacity for undertaking reflective practice, (Knott & Scragg, 2016). This application of learning to practice relates directly to our standards of conduct and practice in that the values of respect for the inherent dignity of the person and of working in a person-centered way, is clearly evident, (Banks, 2012). It further confirms that a partnership and person-centered approach with service users and carers provides for meaningful engagement (Rogers, 1979).

Social workers have long recognized the importance of the social context of the service user and have sought to respond to the needs of people in such a way as to build social or community capacity and to co-create the conditions for health and well-being, (Bronfenbrenner, 1979). This study demonstrates the value of the HLD initiative in this regard.

Planning ahead

The literature (Detering et al., 2010; Jeong et al., 2011; Murray et al., 2016) confirmed the value of ACP regarding enhancing people's experience of quality of life, increasing their autonomy in decision making, and in helping people facing a diagnosis of serious ill health, to achieve peace of mind or a readiness to die.

Respondents agreed planning ahead was valuable and that it provided the people important to them with clarity regarding their hopes, fears, preferences, and wishes for care at the end of life as well as for their death and funeral. All respondents reported having spoken with family members or significant others after the HLD conversation.

Prochaska et al. (1994) described a five-stage model for change which provides a framework to help practitioners understand the complexity involved in the process of making any behavior changes. Applying this model to the findings here is helpful. As described earlier, some participants came to the HLD without the intention of discussing their own

ACP: pre-contemplation stage. Having engaged in the HLD, they moved to the contemplation stage, where they recognized the value of making such plans. There is evidence in the study that participants began discussions with family members about ACP following the HLD, and to this extent moved to the action and maintenance stages of Prochaska's model. It may be reasonable to consider then that the HLD supports participants to "plan ahead" for their final years whether or not they make a written record.

This study broadens the concept of what it means to plan ahead. The idea of creating a legacy based on how they live their lives now was for many respondents a significant outcome of their participation in the HLD. Participants reported a newfound realization that the choices they make in living currently provide the action plan they implement to ensure that when they die, they will be remembered as they had hoped. The HLD focus on both living and dying seems to have enabled this outcome.

Within the overarching strategic context of public health and palliative care, this conceptualization of planning ahead is significant.

"*A public health approach aims to protect and improve the health and quality of life of a community by translating new knowledge and skills into evidence-based, … interventions that will be available to everyone.*" (Stjernsward, Foley, & Ferris, 2007, p. 2). The findings here align with the re-imagining of ACP as described by Abel, Kellehear, Millington Sanders, Taubert, and Kingston (2020) where such conversations should shift focus to include "living" as well as end-of-life-care. It pushes this re-imagining further, by demonstrating merit in bringing ACP into a broadly healthy population and beyond palliative care (Abba, Lloyd-Williams, & Horton, 2019). Furthermore, Kamal et al. (2016) described the difficulties in trying to evaluate many of the growing numbers of new initiatives within the field of palliative care. This study contributes in this regard, in that it provides an evaluation of one community-based initiative, the HLD.

Through their participation in the HLD, respondents described a connection between their reflections on their own mortality, with an experience of an enhanced depth or quality to how they live their lives now, thus increasing their own sense of health and well-being. This is akin to what Mezirow (1994) considers transformative learning. There is some resonance here with the literature, (see Detering et al., 2010) regarding the enhanced quality of life and peace of mind for people who engage in meaningful ACP conversations.

Conclusion

This study informs a public health approach to ACP by offering a model that brings conversations about living and dying into the public domain. As a public-facing, community-based initiative, the HLD has the potential to grow community well-being, as members of the public participate, and then continue their conversations with significant others. The findings suggested that the key to the success of the initiative is ensuring emotional safety for the participants. Having a conversation with significant others is a critical step in the process, which for the participants was more important than completing a written record. Furthermore, there is evidence to suggest that the initiative can increase professionals' confidence and competence in facilitating such delicate conversations. According to participants, it was the experiential learning environment that enabled this growth. This study evidences the benefits of such learning environments which could usefully be incorporated into the current ACP training provided. Further research with a mainly lay and more culturally diverse cohort of respondents would be useful to identify any differences in the findings.

This study provided an evaluation of one community-based initiative and demonstrates the value of the HLD initiative in responding to people's needs in the context of their own lives recognizing social and community influences and impact. Whilst the literature (Abel et al., 2020) highlights the notion that ACP needs to become as much about living as it is about dying and it needs to be mainstreamed in the healthy and younger population (Abba et al., 2019), this study provides a way to do just that.

Furthermore, this study may inform the current development of Public Health Policy and Practice regarding ACP in Northern Ireland, with a virtual HLD currently being developed due to the restrictions on group gatherings within the Covid19 climate.

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ORCID

Deirdre Mc Kenna http://orcid.org/0000-0002-4461-6187
Johanna O'Shea http://orcid.org/0000-0003-3278-2660
Liz Tanner http://orcid.org/0000-0001-8206-0266

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