

Original Article

“At the Foot of a Very Long Ladder”: Discussing the End of Life with Older People and Informal Caregivers

Amanda Clarke, BA (Hons), MA, PhD, RGN,
and Jane Seymour, BA (Hons), MA, PhD, RGN

*Centre for Advanced Studies in Nursing (A.C.), Centre of Academic Primary Care, University of
Aberdeen, Aberdeen; and School of Nursing (J.S.), Queen's Medical Centre, University of Nottingham,
Nottingham, United Kingdom*

Abstract

Context. International policy advocates the development of approaches to raise public awareness about end-of-life-care issues, so that when people face a final illness, they may better articulate their needs for care. This article reports findings from one approach of engaging older members of the general public and informal caregivers in discussions about end-of-life care.

Objectives. To increase understanding of the concerns many older people have around end-of-life issues and provide advice and information to address these.

Methods. Listening events were delivered across the United Kingdom using principles of focus group conduct to facilitate discussions among older people, informal caregivers, and representatives from community groups ($n = 74$) in four workshops. Participants discussed their feelings, experiences, and concerns about the end of life, guided by the booklet *Planning for Choice in End-of-Life Care*, which was piloted in an earlier study.

Results. After framework analysis, three themes arose: communicating about end-of-life issues, factors that influence individuals' concerns about death and dying, and advance care planning. The heterogeneity of stories told not only illustrates how people's responses and needs at the end of life vary greatly but also reveals shared reactions, experiences, and some confusion. The stories also demonstrate people's willingness to engage with concerns associated with the end of life and their conviction that this is an important area of community action and development.

Conclusion. Further community-based solutions to questions of quality of death need to be found, encouraged by programs of public education. *J Pain Symptom Manage* 2010;40:857–869. © 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Older people, informal caregivers, end-of-life care, palliative care, death and dying, public awareness

Address correspondence to: Amanda Clarke, BA (Hons), MA, PhD, RGN, Centre for Advanced Studies in Nursing, Centre of Academic Primary Care, University of Aberdeen, Foresterhill Health Centre,

Westburn Road, Aberdeen AB25 2AY, United Kingdom. E-mail: a.e.clarke@abdn.ac.uk

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Introduction

The rising incidence of comorbidity, disability, and extreme general frailty in older age not only makes prognostication complex but also means that many older people receive inappropriate end-of-life care that is out of step with their needs, wishes, and preferences.¹ Current policy direction reflects the recognition that palliative and end-of-life care are not only about the management of the last days of life but also about supporting people with long-term health conditions to live as comfortably as possible until they die.² A key emphasis is on enabling participation in care planning, both during and in advance of any illness, taking into account the individual's values and preferences.^{3,4} In England, a National End-of-Life Care Strategy⁵ advocates the development of approaches for raising public awareness about end-of-life care issues, so that when people face a final illness, they may better articulate their needs for care. This is seen as a key way of providing patient-centered care.⁵ This article reports findings from one approach of engaging older members of the general public and informal caregivers in discussion about end-of-life care and reflects on the methodological issues involved in the process, with a view of informing development of work to raise public awareness.

Background

There has been comparatively little research concerning the views of older members of the public about end-of-life care, and there is inadequate understanding of the challenges involved in attempting to elicit these views.^{6–8} In the English End-of-Life Care Strategy,⁵ it is argued that there persists in the United Kingdom a lack of public openness about death, which is likely to have a number of negative consequences, including fear of the process of dying, lack of knowledge about how to request and access services, lack of openness between close family members when a person is dying, and isolation of the bereaved. A number of influential theses have promoted the idea that prevailing social attitudes to death in the United Kingdom and other resource-rich countries involve regarding it as “taboo,” “pornographic,”⁹ or “wild.”¹⁰ For many years, it has

been argued that such attitudes lead to a denial of the inevitability of death^{11,12} and its “sequestration” (both as an event and a topic of conversation) from daily life.¹³ In the last 15 years, a largely theoretical critique has developed about such claims,^{14,15} suggesting that attitudes are much more complex than the “death denial” literature suggests. However, there has been relatively little empirical examination of their resonance in the perspectives of ordinary members of the general public and no evaluation of the implications of these for policy and practice. Those studies that do exist reveal diversity. In a seminal interview-based study from Scotland,¹⁶ a quick painless death was perceived by some older respondents to be “good” but, equally, a death that gives time for a reunion with family and to settle affairs was regarded positively. Such research shows that older people perceive many dilemmas in achieving a balance between their desire for autonomy and the need for care and support at the end of life.^{7,17–19} They value a degree of choice and control but, concomitantly, recognize that practical and moral problems, such as the desire not to “burden” their families or “take” resources from younger people, may take precedence over their own preferences.^{19–21} Some survey-based studies reveal that, as people age, their preferences for home-based care at the end of life and at the time of death are subject to change, with alternative preferences expressed for either hospice or hospital care.^{22,23} Similarly, where people have had experience of caring for someone who has been terminally ill, they appear to favor death at home less than others.²⁴ Stances to end-of-life decision making may relate to the uncertainty of taking certain courses of action.^{17,20} Arber et al.¹⁹ stress that it must not be assumed that older people are autonomous individual decision makers but may draw on different aspects of their lives and previous experiences when considering complex end-of-life care issues. Furthermore, older people are not necessarily preoccupied with negative thoughts of death and dying; for example, biographical research with 23 individuals aged 60–96 years suggests that, even in the face of serious progressive illness, opportunities are perceived for living, enjoying activities, and looking forward to the future.^{24,25}

This article reports on four “listening events” held in the United Kingdom and offers some reflections on the process of participation, attention to which is often neglected.²⁶ Kendall et al.’s²⁷ systematic literature review identified only small numbers of publications related to the practicalities of conducting end-of-life research. We start, therefore, by describing the organization and delivery of the events. We then present key findings under three main themes: communicating about the end of life, factors that influence individuals’ concerns about death and dying, and advance care planning (ACP).

Methods

After our earlier work in the area,^{28,29} Help the Aged, an international charity that campaigns for older people, commissioned us to deliver four listening events in diverse communities across the United Kingdom to increase understanding of the concerns older people express around end-of-life issues and to provide them with information to address these. The events are described in detail elsewhere.³⁰

Ethical Approval

The study was reviewed by a University Research Ethics Committee for healthy volunteers. Before the events, potential participants were sent an information leaflet and consent form, including consent to be photographed and to use their anonymized comments in subsequent reports.

The Listening Events

A convenience sample was used; participants were self-selected, having responded to publicity about the events. Recognizing the importance of gathering diverse views and engaging with individuals and those who are affiliated with organizations,³¹ we used a range of recruitment methods, including advertisements in the local press/community group magazines, letters/e-mails to representatives of older people groups and known contacts. The listening events were held across four areas to reflect Help the Aged’s engagement in different communities around the United Kingdom and to gather a diverse range of views (rather than to specifically investigate

possible differences): North England (23 participants); South England (15 participants); Scotland (11 participants); and Wales (25 participants) (Table 1). There were no apparent differences in the data discussed here in terms of locality, although it was apparent that ethical and legal issues were different in Scotland. This sometimes added to the confusion surrounding terminology and was highlighted when introducing the booklet *Planning for Choice in End-of-Life Care*.³²

Although it was people aged older than 60 years who comprised most of the participants, some younger people who had a particular interest or involvement in end-of-life care (e.g., hospice volunteers) also attended. It is indicated in the text where the views of older individuals, representatives of groups for older people, or members of the team are reported.

Principles of focus group conduct were used to facilitate the discussions.^{33,34} Each group was guided by a researcher with help from members of the Help the Aged team and two older volunteers.³⁵ We referred to INVOLVE³⁶ guidelines to work in partnership with the volunteers, for example, suggesting that they worked in pairs for support. (INVOLVE is a U.K. advisory group funded by the National Institute for Health Research. Its role is to support and promote active public involvement in National Health Service, public health, and social care research.) One team member observed participants for distress and provided support, if necessary, in a designated room. Team members were available to provide information or advice as required, together with a range of information leaflets.

Each event ran over several hours, with breaks for refreshments and lunch. After an

Table 1
Listening-Event Participants

Seventy-four older people participated in the events. Most of them comprised older members of the general public, that is:

- People aged from early 60s to late 80s, of whom one-third were men and two-thirds women

Some of these participants were also:

- Caregivers for a spouse, parent, or other relative/friend
- Representatives and/or members of older people’s groups (such as Speaking Up for Our Age group, Better Government for Older People, 50-plus groups, Chinese Elders Support Group [accompanied by an interpreter])

introduction to the background and aims of the events and allowing time for questions, participants were invited to join small discussion groups (maximum participants, 10). The day was divided into morning and afternoon sessions.

In the morning, “open discussions” gave participants the opportunity to relate their own experiences and concerns about death and dying (Table 2), because our previous experience demonstrated the importance of allowing time for people to tell their stories.⁷ This also reflects the methods used by others who have accessed older people’s views about their perspectives, needs, and service provision.^{26,37,38}

In the afternoon, “structured discussions” were facilitated using the booklet *Planning for Choice in End-of-Life Care*.³² The booklet, which was coauthored by five older people, uses vignettes to introduce care planning and communication at the end of life. The method has been used successfully to address sensitive subjects before.^{33,39}

Data Collection and Analysis

Because the emphasis was on *listening* to people’s concerns about a potentially emotional topic—death and dying—we took the decision not to record discussions in case the presence of a recorder might have an inhibitory impact on some participants and seem insensitive. Data from the listening events were collected by written notes to record the main issues and concerns people had about the end of life and care. As far as possible, dialogue was noted as it occurred, allowing the original sense and context of the comments to be retained. One of the investigators (A. C.) carried out an initial analysis of data, guided by the principles of the Framework Approach to facilitate rigorous and transparent management and analysis of data.⁴⁰ Framework Analysis

uses a thematic framework to classify and organize data according to key themes, concepts, and emergent categories. All team members, including the older volunteers, read and commented on this analysis, adding to and amending the themes until an agreed framework of themes was developed.

Analyzing the data in this way allowed participants’ views, circumstances, and experiences to be explored within a common framework that was both grounded in and informed by their stories. This enabled the full range of perceptions and experiences to be compared and contrasted, ensured that the analysis was thorough and consistent, and that links with participants’ own words were retained.

Evaluation

To evaluate the impact of engaging in the listening events, participants were asked to complete an anonymous questionnaire, which included questions about the organization, venue, facilitation and content of the day, and space for qualitative comments. From 74 participants, 45 questionnaires were returned: an overall response rate of 60% (some participants attended as couples and may have completed and returned one questionnaire between them).

Results

The results are reported in the following sections under three main themes: communicating about end-of-life issues, factors that influence individuals’ concerns about death and dying, and ACP. These findings are from data collected from both the morning and afternoon discussions. Participants’ comments specifically relating to their evaluative views about the booklet *Planning for Choice in End-of-Life Care*³² are not reported here.

The extracts from the focus groups are referred to in the text using an area identity (ID) and participant ID number within that area: P = participant, S = Scotland, W = Wales, SE = Southern England, and NE = Northern England. Participants’ comments have been included to illustrate the themes discussed. They did not always state when their experiences had occurred or whether their comments were based on perceptions, expectations, or experiences;

Table 2
Suggested Questions for Facilitators

What interested you in attending this event?
What does the phrase “end of life” mean to you?
In relation to end-of-life care, please could you say something about:
– Your feelings about discussing this topic?
– Your experiences?
– Your concerns or hopes?

however, we report when this was explicit. Webb and Kevern⁴¹ advise that the intention of focus groups should not be to describe the meaning of individual “pure” experiences, because group interaction can “contaminate” the discussion about personal experiences.

Communicating About End-of-Life Issues

Talking About the End of Life in a Public Forum.

Events appeared to be seen as a “safe place” to share experiences of loss, as highlighted when two team members from Help the Aged asked if they could share their own experiences of the death of a parent. Most participants stated that this was the first time they had spoken about these experiences in public. Although people often cried as they told their stories (and were supported by other group members), they were keen to continue, indicating that the act of telling is cathartic in itself. As one woman said, “I think a little cry helps” (NE/P1). One participant who described her sister’s assisted death in The Netherlands expressed her gratitude that she had the opportunity to tell the story. Over the four events, two people became visibly distressed during the small group discussions and took a break, supported by a team member.

One or two participants in each group said that, initially, they had been “put off” from the event because of the phrase “end-of-life” care. Apprehension among others seemed to be overridden by their need for knowledge about the end of life. For example, the four Chinese participants explained that, although it was “unlucky” to discuss death in Chinese culture, their fears about this were superseded by their desire to gain more information. The main purpose for the few participants who had attended the events as representatives of local groups for older people was to disseminate the information to their peers; for example, the Chinese participants said that they wanted to find out about choices at the end of life and pass this knowledge onto their communities.

Unsurprisingly, because they had taken the decision to attend the event, most participants said that they were more comfortable discussing their concerns about death and dying in a group. They perceived attendance both as a means of accessing help in thinking about the issue and of gaining information where

none was usually available to them. The reasons expressed by the participants attending the events are illustrated in Table 3.

Attendees felt that similar events should be “made available to everyone,” including younger people:

This is the first time I’ve seen anyone talk about dying or end of life. It’s an issue that really needs to be opened up and the spotlight put on it. (W/P10)

Another man wrote in the questionnaire to evaluate the event:

Gave me food for thought...I had already planned and paid for my own funeral to save the expense falling on my family, but I had not given much thought to the events leading up to it. I now have a better idea how my end of life should be.

A common feeling was that, in society in general, death and dying are talked about less than that in the past. Participants in Scotland reflected on their childhoods and how neighbors would help with childbirth and death, regretting that this did not happen now. This view was reflected in other parts of the country where events occurred. Participants described how death was “more visible” in the past; many people died at home, and the body was laid out so that people could pay their respects. They also described funerals where the whole community gathered to support the bereaved:

In the old days, there was someone who could help with birth and with preparing the body of someone who died who would

Table 3
Participants’ Reasons for Attending the Listening Events

“I’ve never been to [a] group like this before but I worry about what will happen to me when I get older because I’ve no children. I want to learn new things” (W/P2).
“It’s important to talk and share experiences. You can’t understand these issues by reading a book or reading about it on the internet” (W/P5).
“I can’t cope with hearing about dying, it feels like giving up on life, but I do need help facing up to it” (S/P6).
“People without family and friends find their voices are not listened to; they don’t have a push from behind. When you get to a certain age, you’re a ‘none person’. A lot of people don’t want to join groups, but if you’re independent, you’re not listened to. I’m here on behalf of people like me who have very little clout” (W/P21).

be living in the same street, there was community. (WP/12)

Talking About the End of Life with Family Members, Health Professionals, and Others. A variety of views were expressed concerning discussing the end of life with relatives and others. One woman in SE said that her family was unwilling to talk: "My family say talking about death is being morbid. But it's not, it's realistic" (SE/P4). However, the other members of her group felt "We can have a laugh about it sometimes with our families." It was the death of a family member that often prompted people to inform their families about their plans for their own funeral. Some participants preferred not to talk to their families about death: "I get very emotional, I don't want them to know if I'm worried" (NE/P6). Others said that they felt most comfortable talking about death and dying with their peers, as one woman explained:

...my friend said she didn't feel safe talking about dying with people other than those of her own age—she felt that she might be patronized. (W/P9)

Spiritual aspects of death and dying were important for some participants who described how their faith and/or belief in an afterlife were sources of comfort when reflecting on death. These participants perceived that the clergies (of all faiths) were very supportive—at the end of life and in planning and conducting funeral services—but participants felt that health care professionals needed to respect the spiritual and religious needs of all patients:

We live in a secular society. In hospital, death is very clinical. My friend was on a ventilator and when I asked about chaplaincy services, I was considered a loony. The spiritual side is neglected. (S/P4)

Factors That Influence Individuals' Concerns About the End of Life

Whether people felt that they would want to continue with medical treatment, should they become seriously ill or incapacitated in the future, seemed influenced by a number of factors including unrelieved pain, experiences of poor end-of-life care, fears about dying alone,

not having a choice over place of death, and confusion about end-of-life care.

Being in Pain, Being Incapacitated, or Receiving Poor Care. Participants were worried about being ill and in pain. In this situation, they expressed the desire to discontinue treatment, such as artificial ventilation, which may prolong dying: "When you're curled up in the fetal position in pain, turn off the machine" (NE/P12). It should be noted that no stories were recorded about people actually experiencing others dying in pain, and participants appeared skeptical about whether pain control could be achieved. In one group, when a retired nurse commented that there was no need for anyone to die in pain now, it was observed that all other members of the group raised their eyebrows in disbelief. Thoughts of being in pain seemed to lead some to state that they agreed with euthanasia: "If I could be given a pill to take when I wanted to go—I would take it" (S/P9). Similarly, experiences of poor care and worries about loss of dignity appeared to influence this man's view that he did not want to be resuscitated:

I've been in and out of hospital all my life. I'm concerned about what will happen to me when I can no longer do things for myself. My wife died three years ago. The treatment wasn't good. I'd promised her she wouldn't go into hospital but eventually she had to be admitted—she was in a coma. My experiences have led me to advise the family that I wouldn't want to be resuscitated. (W/P13)

Dying Alone. Fear of dying alone at the end of life was a common fear among participants, as this man describes:

I've moved to a flat and there's nobody in the block. I worry about dying alone and suffering a stroke. If I took ill—what would happen? It's the indignity of dying alone.

He felt that media reports "triggered worrying about these things," although he had personal experience of such an incident: "I attend a reading group and one member had been dead for five days before anyone found them" (NE/P22).

Linked to the fear of dying alone was a hope that families would be near at the time of

death. Chinese participants emphasized this, describing how “bonding” between parents and children was very important in Chinese culture; not having their children present (especially the eldest son) when ill or dying would be “devastating.”

Lack of Choice About Place of Care at the End of Life. Discussions about place of care⁴² were raised spontaneously by the participants. There was debate whether patients had a real choice concerning where they died:

Do you have a choice? My uncle had a stroke and went into a community hospital and then a residential hospital. But he didn't like it in there. He wanted to go home, but he couldn't. (S/P3)

Or whether caregivers had a choice:

When my mother-in-law died, we didn't have choice. She was coming home to us—there was no choice. We were told she was cured but she came to us in May and died in October. (W/P12)

A common desire among participants was to die in their sleep; sometimes, this was precipitated by a fear of dying in a care home or hospital: “Most of us want to die in our sleep, but worry it won't happen. I worry I'll go into a geriatric ward and be left there” (W/P1).

Other participants raised concerns about “being a burden” on their families should they become incapacitated in the future; this appeared to influence their expressed preferences for place of care:

I'm worried about being on my own, but equally concerned at the thought of going into care or inflicting on my children—they have their own children and responsibilities. (NE/P7)

Lack of Understanding About Euthanasia and Related Issues. It was evident from people's comments that there was an element of confusion surrounding end-of-life care (Table 4 provides widely accepted definitions). This means that people may be unnecessarily anxious about the process of dying. The statements in Table 5 reveal that there was lack of understanding about what is permissible in medical treatment at the end of life and what

constitutes euthanasia. Similar confusion surrounded issues associated with ACP.

Advance Care Planning

ACP is a voluntary *process* of discussion between an individual and his or her care providers, which may or may not also include family and friends, and will usually occur in the context of an anticipated future loss of capacity/communication because of illness.⁴⁴ We used the booklet *Planning for Choice in End-of-Life Care* to prompt discussion about ACP.³² With the exception of planning for funerals, which many people had done, the minority of participants who were familiar with ACP talked about living wills.

Advance Directives. It was apparent from the listening events that there was some confusion not only about the terminology but also about the processes involved in making advance statements. At the time the listening events

Table 4
Definitions of Euthanasia, Life-Prolonging Treatments, Advance Decisions, and ACP^a

A widely accepted definition of euthanasia is “Euthanasia is killing on request and is defined as: a doctor intentionally killing a person by the administration of drugs at that person's voluntary and competent request.”⁴³

It is recognized that where death is inevitable, then life-prolonging treatments, such as resuscitation, artificial ventilation, dialysis, or artificial feeding may be withdrawn or withheld. In such cases, the goal of medicine becomes the relief of symptoms. The provision of “basic care” and comfort must be provided and can never be withheld. It is acknowledged that, sometimes, giving adequate symptom control or withholding or withdrawing life-prolonging treatments may hasten a death that is already expected. This is not euthanasia.³¹

Advance decisions only come into effect when the individual has lost capacity to give or refuse consent and formalize what individuals do NOT wish to happen to them. They are a legally binding document if valid and applicable; they must be related to a specific treatment and may specify circumstances, such as “If I cannot swallow...” For the first time, the Mental Capacity Act makes legal provision for the completion of advance decisions.⁴⁴

The outcome of ACP includes the completion of 1) a statement of general values and views about care and treatment. In the United Kingdom, these are known as statements of “wishes and preferences” and are promoted as a useful record to guide future care; or 2) an advance decision to refuse medical treatment in defined circumstances.⁴⁴

^aLay summaries of these definitions were provided for participants in the booklet *Planning for Choice in End-of-Life Care*.³¹

Table 5
**Participants' Comments About Medical
 Treatment at the End of Life and Euthanasia**

"I would like to know about tube feeding: why do the physio's give treatment to a dying patient?" (W/P25)
"Morphine is given to hasten death and no reasons why—isn't that euthanasia?" (S/P2)
"But what happens if fluids or feeding are withdrawn? You hear about people starving to death and it's supposed to be painful." (W/P24)
"Euthanasia—is one stop closer to assumptions that the 'winging wrinklies' can be gotten rid of." (S/P1)
"A friend of mine in for assessment—she's not able to take on board all options put to her—people can be manipulated." (SP/7)

were held, a new Mental Capacity Act⁴⁵ was introduced in England, making it possible for the first time to draw up a potentially legally binding "advance decision" for the refusal of medical treatment. We introduced these as "living wills."

Only three participants described how they had made a living will. One woman said she was prompted to do so after having pneumonia and added, "It wasn't a difficult process. My friend's done it" (W/P26). Other reasons for writing a living will included not wanting resuscitation in terminal illness or wanting to record decisions in advance of incapacity or as a means of addressing the problem of family members' reluctance to discuss end-of-life issues by leaving instructions. In contrast, others said they would prefer to leave decisions about treatment and care to their families: "I haven't made a living will, but perhaps I'm naïve; I trust my children" (W/P23).

Most participants said that they had not heard of living wills before, and some participants felt that writing a living will was something they would now consider. One man said that he had suffered a heart attack and felt that the "time was right" to make his wishes known. He was keen to do this for himself, because he did not want his wife or anyone else to make decisions for him.

The Chinese participants said that they would not want or be able to formalize their wishes in written form. A man from a different focus group was also concerned about formalizing an advance care plan:

My mother is 89, she had a stroke, was kept on a hospital trolley for three days, she was incontinent, couldn't speak or walk. But

her condition improved. She now enjoys life. She watches TV, visits family and has a good quality of life. In those first few days, you couldn't have given her any hope. This highlights the need for safeguards in living wills. (W/P19)

For this woman, the idea of expressing wishes rather than putting them in writing was preferred:

I've told them not to bother coming to see me if I don't know they're there ... Women get hair on their faces as they get older, they get left whilst men get shaved ... I said to my husband, "If I've grown a moustache and I'm unconscious, don't you dare bring anyone in to see me." (NE/P20)

Participants pointed to the need for health care staff to collect information about wishes and preferences, perhaps, by requesting biographical information. One woman described the person-centered care her dying husband had received: "When my husband went to hospital, they asked me to make a diary of his life. Things he liked, things he didn't" (W/P9).

Methodological Reflections and Limitations

One of the disadvantages of focus groups is that discussion may be dominated by vocal participants.⁴⁶ It may be difficult to achieve a balance between giving each participant time to articulate matters of personal importance and ensuring that everyone who wants to speak feels able to do so. Group consensus can be undermined if some participants are reluctant to contradict others or when the topic under discussion may cause embarrassment.^{33,46} In presenting our findings, we have indicated where areas of agreement and disagreement appeared to occur.⁴⁷ When personal experiences were discussed, the small size and structure of the groups appeared to give participants comfort and reassurance from the empathy of others.⁴⁸ This, particularly, was apparent in the group from SE, which mainly comprised members of a local action group for older people; when one woman described the death of a relative and began to cry, the other women gathered around to comfort her. Providing a familiar and safe environment is especially pertinent

for discussions of a sensitive nature, which may raise powerful emotions.

There is some discrepancy in the literature regarding the use of focus groups for investigating sensitive issues;⁴⁹ however, we endorse this method in this context, provided the process is thoughtfully considered and guided by older people themselves, experienced researchers, and health practitioners, as ours here. Almost all participants were positive about the event; for example, all who returned a questionnaire strongly agreed or agreed that the day was worthwhile, and most of them (97%) strongly agreed or agreed that the content was relevant to their needs or the needs of their organization; 98% strongly agreed or agreed that opportunities to participate were appropriate; and 100% indicated that they felt able to contribute in the small groups. Nevertheless, one person was deeply unhappy that an issue of particular importance to him (regarding funeral payments) was not the sole focus of the event he attended and went as far as putting this in writing to us. On reflection, the sheer lack of opportunities to express strongly held views about end-of-life care, together with the often-emotive nature of the topic, means that this may always be a risk. From our experience, it is crucial to allow plenty of time for discussions and have at least two facilitators and an observer who is free to offer support if participants appear distressed. Dedicated time for debriefing after the event should be planned in advance, giving team members the opportunity to articulate any personal feelings and emotions raised by the events as well as any challenges encountered. We have found that facilitating events around this topic can be emotionally and physically demanding.

Although we do not claim to make generalizations from a sample of 74 people, we are confident that we collected a range of views from older adults and their representatives living in different localities in the community and with different sociodemographic and cultural circumstances. We acknowledge that our sample underrepresents very frail and/or disabled older people and elders from black and minority communities, with the exception of elders from the Chinese community ($n = 4$). There tends to be an assumption of a monolithic culture in policy literature, despite countries, such as the United Kingdom, being

multicultural. Both distinct similarities and differences between the attitudes and views of white and Chinese elders living in the United Kingdom toward end-of-life care have been reported;⁵⁰ more research, therefore, is needed among a range of ethnic groups. Furthermore, given the self-selecting nature of recruitment, those who agreed to participate, clearly, were open to discussions of this nature; not all older people wish to talk about death and dying. Despite this, we believe our study highlights that some older people are willing and want to talk about issues surrounding the end of life. Our findings add a valuable contribution to the little research to date about the views and experiences of older people living in the U.K. community, who are not necessarily experiencing a serious medical condition.²¹

Discussion

We are aware of the heterogeneity of stances toward the discussion of death and dying: for each older person who participated in the events, there are likely to be many more who would never wish to do this and for whom such activity would be regarded as unacceptable. Our findings revealed that participants' reported apprehension about discussing end-of-life issues was overridden by their desire to know more about the decisions and choices available to them as they approached the end of their lives. Many said that they had not been given the opportunity to discuss the subject before—either with families, friends, or health professionals, or in a public setting—and appreciated the opportunity to tell their stories and express their concerns.²⁹ Unsurprisingly, because people had volunteered to take part, they expressed a preference to discuss such issues in a group rather than on their own.

Participants felt that death and dying are talked about less than in the past, when they witnessed people being cared for before and after death in the community. In contrast, most deaths today occur in hospitals; many people do not have to care for a family member or a close friend dying until they are into their midlife years or later and, until this time, few would have seen a dead body.⁵¹ The view that death and dying are subjects

that should be talked about more openly is reflected by a national survey undertaken in Scotland: 70% of 668 members of the public felt that there was not enough discussion about death and dying within the Scottish society.⁵²

For some participants, the spiritual dimension at the end of life was important. Many studies have found that older people with a religious belief find a source of comfort in their faith, particularly as they approach the end of life.^{53,54} Our participants pointed to the welcome support they had received from clergies of different faiths at times of illness and bereavement and felt able to talk to them about their concerns. This, perhaps, points to the need to widen the debate about end-of-life care to include members of society who have a professional interest in death, such as faith leaders, funeral directors, and the police,⁵⁵ although, as Kellehear⁵⁶ heeds, we must beware the “professionalization” of death at the expense of excluding the general public.⁵⁷

It is interesting to compare our findings with a survey undertaken with members of the general public in the United Kingdom. An online survey of 2,246 adults was undertaken by YouGov for Dignity in Dying,⁵⁸ a charity that promotes the choice of individuals to have an assisted death. The survey asked respondents about their fears about dying. These results must be treated with caution because of the survey commissioner and the limited ability of the method to uncover complex issues. Nevertheless, they provide a helpful comparison with our findings, given the lack of academic research in the area. The Dignity in Dying survey found that the greatest concern for 32% of the respondents was solitary death.⁵⁸ Fear of dying alone was stronger in those who lived with relatives than those who lived alone, indicating that there may be an acceptance among those who live alone that they may also face dying alone. Being left alone at the end of life was a common fear among listening-event participants. This is particularly pertinent, given predictions that, by 2021, the population of older people living alone in the United Kingdom will have increased by as much as one-third because of social changes, such as more people choosing not to have children.⁵⁹ The Dignity in Dying survey also found that

people older than 55 years—particularly those who lived alone—were more concerned about the practicalities surrounding dying than younger people. The importance of having treatment wishes respected and dying in a place of their choice increased with age.⁵⁸

In an essay on aging and the ethics of care, it has been observed that we lack both the language and a set of policies to adequately inform the sensitive delivery of care for older people whose experiences may not fit with the policy rhetoric of control and independence.⁶⁰ There was a wide perception among listening-event participants that there were no real choices to be made with respect to the end of life; participants reflected on the inequalities of care they had witnessed, experienced, or heard reported. Participants were well aware that the health services available might be unable to deliver some things that are “chosen,” such as death at home.^{20,59} Some felt that lack of information about illness and end-of-life care precluded informed choices.¹⁷

The need for up-to-date and accurate information about end-of-life care was evident from our findings. Although participants appeared to accept death as inevitable, this did not stop them having anxieties about the process of dying.^{20,21} Being in pain at the end of life was one of participants’ greatest concerns; similarly, the Dignity in Dying survey found that one-fifth of respondents indicated that their greatest fear was dying with inadequate pain relief.⁵⁸

Supporting other studies,^{61,62} it was evident from people’s comments that there was an element of confusion surrounding end-of-life care: not only about realistic pain management and treatment but also concerning when treatment can be withdrawn and what constitutes euthanasia in law. We were able to distribute the booklet *Planning for Choice in End-of-Life Care*³² to ensure that participants had information about these issues, but participants’ misapprehensions highlight the need for public education in this area.

The confusion may reflect the context in which initiatives in England and Wales to support the Mental Capacity Act⁴⁵ were introduced, because the latter was widely reported in the media as a “back door to euthanasia.”⁶³ This was probably because of parallel debates

about the legalization of assisted dying that was occurring simultaneously. This seems to have affected the way in which members of the public perceive ACP, with some worrying that the completion of advance directives may lead to medical actions akin to “pulling the plug” or out of step with the real intent of the person in question.⁷ This might account for none of the participants in the listening events stating that they had delegated advance decisions to health professionals.^{7,19} Concerns with regard to possible changes in care preferences over time may be another reason for this reluctance;^{7,21} indeed, some listening-event participants preferred the idea of expressing their wishes rather than putting them in writing in case they changed their minds about care and treatment. Although some participants said that they wished to make decisions now about the future in order not to place the burden on their families,^{19,20,21} a few preferred to leave decision making to their families.

Although Woolhead et al.¹⁷ found that older people were in favor of self-determined death, citing living wills as promoting individual choice; in our study, only a few participants had specific views about particular medical treatments. At all listening events, people discussed the seemingly mundane “small” things that would be important to them should they lose the capacity to help themselves in the future, such as putting on face cream. This suggests that broader approaches are needed to facilitate discussion on issues surrounding the end of life. These discussions must include a focus on the personal goals, values, and everyday preferences of individuals, and draw on different aspects of people’s past, present, and future lives. A qualitative evaluation of a U.K.-based, lay-led, self-management course that incorporated ACP in the training highlighted the importance of being sensitive to people’s biographies when facilitating discussions about the end of life.⁶²

Conclusion

The events described in this article not only illustrate how older people’s responses and needs at the end of life vary greatly but also reveal shared reactions, experiences, and some confusion from which practitioners, researchers, and

policy makers can learn. Listening and acting on the views of the public should be an integral part of planning and delivering end-of-life care to ensure that such care is sensitive to their needs and experiences. Participants’ confusion about ethical and legal issues in end-of-life care management and decisions also highlights the need for greater awareness and discussion in this area.

Findings also demonstrate people’s willingness to engage with end-of-life issues and their conviction that this is an important area of community action and development. Since the time the listening events took place, there has been continued and growing public interest in end-of-life care issues.^{4,5,57,58} Furthermore, innovative community-based solutions to questions of quality of death need to be found that seek to promote, as in Kellehear’s and Young’s⁵⁵ vision, the emergence of new forms of participatory social action, encouraged by programs of public education. As one participant in the listening events acknowledged, “There is a need for education here. I feel we are the foot of a very long ladder.”

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