

End of life choices and storytelling – exploring preferences and conflicts

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As people are living longer, their needs for health and social care at the end of life (EoL) are increasing. People are encouraged to make choices about their EoL, but doing so is a complex process, and there is currently little research into how – and if – people engage with this. Our study investigated older people’s EoL choice making, through twenty interviews with people aged 70 plus. We found that storytelling enabled people to make sense of and reflect on previous EoL experiences, and form, elaborate on, and justify their own EoL preferences. Stories also brought to the fore the inherent conflicts in making EoL choices, and emphasised that in reality choices for many are limited.

Key words: care, death, dying, end of life, storytelling

With people living longer and facing increasing health and social care needs in their later years (Kelly), making choices about end of life (EoL) care is framed as being necessary for a positive ageing experience and a “good death” (Borgstrom). Policy rhetoric in the UK, as well as in countries including the USA, Canada, Australia, and parts of Europe (see Borgstrom; Brinkman-Stoppelenburg et al., Collyer et al.; Wolf et al.), focuses on individuals’ right to make choices about their EoL (Department of Health; Dying Matters; National Palliative and End of Life Care Partnership), including who provides care, where it is provided, what is provided, and place of death (Borgstrom and Walter; Department of Health). Making choices is deemed as “a triumph over the potential for failure and lack of control that death and dying present” (Borgstrom 706). Choice is frequently equated with dying at home, with this seen by governments and policymakers as preferable to a hospital death (Bone et al.; Collyer et al.; Froggatt). However, critics of the EoL choice agenda note

that EoL choices exist “within a complex sphere of interrelationships, vulnerabilities and interdependencies” (Collyer et al.). Choices often depend upon an individual’s family and friends (Considine and Miller), and health and care structures and systems, and have risks for the people involved in enacting these choices (Wilson et al.). This can lead to potential tensions arising in that “the meeting of one person’s needs may be at the expense of another party’s preferences” (Froggatt 199). Caring for a dying family member can pose physical, emotional, and social challenges, and not all individuals will have family members willing and able to deal with this (Carlander et al.; Considine and Miller; Wilson et al.), meaning that it may not be possible for choices to be enacted (Borgstrom; Considine and Miller; Froggatt; Wilson et al.). Care home deaths are seen as preferable to hospital deaths (Bone et al.) but choices here are dependent on room availability (Froggatt) and financial considerations. Even articulating EoL choices can be problematic for individuals (Borgstrom), as there are still tensions around talking about death and dying, both within families and with health care professionals (Costello; Fleming et al.; Tagney; Venkatsalu et al.).

Making, expressing, and enacting EoL preferences is therefore a complex process, and there is currently little research into how – and if – people engage with this. Our study explored older people’s EoL choice making, through twenty interviews with people aged 70 plus. Throughout the interviews, all participants shared stories of their own experiences, as well as those of family, friends, and acquaintances, and we explore in this paper how individuals used storytelling to form and express their EoL preferences, and grapple with the potential conflicts inherent in these choices.

EoL Issues and Storytelling

Choice is traditionally presented as a rational decision making process, but choices in most things are not actually made in this way, and in particular around EoL issues (Collyer et al.,

Wolfs et al). Making choices firstly requires thinking about and discussing EoL preferences, as advocated by the Dying Matters movement and authors such as Boyd and Murray, Costello, McGrath et al, and Semino et al. Early discussions about people's EoL wishes are argued to be important in order to make death as positive an experience as possible, both for the individual and for those around them (Boyd and Murray; Semino et al.). There are indications that this is not common practice, however. Costello notes the continuing reluctance of doctors and nurses, as well as the general public, to talk about death. Participants in the UK-based study by Fleming et al. (all over 95 years old) were willing to discuss EoL preferences in the interviews, but had rarely spoken about this with family and care professionals. Venkatsalu et al. claim that death is still a taboo subject in some cultures, based on qualitative research with older South Asians living in East London. People may be reluctant to talk about dying due to a range of factors, including fear of causing upset or offence, lack of knowledge, uncertainty about their own beliefs, and fear of death itself (Tagney). Even when people indicate they are happy to talk to their friends and family about death and dying, this may not actually result in clear understanding about an individual's wishes, or a plan for their EoL (Hickey and Quinn). For example, Borgstrom's qualitative ethnographic research with two hospice patients found that uncertainty about the prognosis of their disease and their future care requirements hampered their ability to make EoL choices.

Storytelling is used both in traditional cultures and in modern research to counter these difficulties in holding conversations about death and dying, Baydala et al. describe the use of storytelling by an Aboriginal tribe in Canada, to share knowledge about the process of death and dying, care for an individual at the EoL, honour their passing, and cope with grief. Baydala et al. note this use of storytelling as a "form of meaningful caring at end of life" (172) and an antidote to the "technical and rational biomedical frameworks of understanding" (159) in modern health care settings, that can overshadow personal meanings of EoL care,

dying, and death. In a research setting, Williams et al. found that facilitating the production of digital stories about Māori EoL caregiving was an effective way of engaging the indigenous New Zealand population in research about EoL care, and resulted in digital resources that could be used for healthcare education and training.

Storytelling has been used to understand patients' experiences in health and social care research (Underwood-Lee and Thimbleby). de Jong and Clarke collected stories from 15 people involved in palliative care, including patients, caregivers, physicians, and nurses, and identified the themes in narratives of "good" and "bad" deaths, with the aim of using this understanding to improve EoL care. A good death involved lack of pain, feelings of a life well lived, and a sense of community, whereas a bad death involved pain and loss of control and independence. In America, DelVecchio Good et al. and Wittenberg-Lyles et al. both analysed physicians' narratives of patients' deaths, to understand what physicians saw as quality EoL care and a good death. Both studies found that a relationship between the practitioner and patient that overcame the patient's feelings of isolation and abandonment was key to a good death. Semino et al. similarly found that UK-based hospice managers used narratives to describe good deaths in terms of "peacefulness, symptom control, frank conversations, acceptance and openness to physical and emotional support", whereas a bad death involved "conflict within families, lack of acceptance, rejection of physical and emotional support, and physical and emotional distress" (681). At an individual level, storytelling has been explored in palliative care, as a way to better understand patients' preferences for their EoL. Southall provides an illustrative case study of a UK palliative care patient telling a story about his time in Africa to a health care professional, which led to the patient reflecting on and discussing his treatment and EoL wishes. In China, Chan and Pang found that a storytelling approach helped engage frail nursing home residents in advance care

planning in a culturally sensitive way, by reflecting on their treatment preferences in the context of their values and life goals.

Storytelling can also provide opportunities to understand and create meaning from life and EoL experiences, for patients, caregivers, and health professionals (Benzein and Saveman; de Jong and Clarke; Lindsay), by enabling the teller to order, reflect on, and make sense of past experiences (McGeough). For people facing death, stories can help them to make sense of their illness and death as part of their wider life experience (Bailey; Bingley et al.; Churchill and Churchill; Schenck and Roscoe). Nakashima and Canda found that creating life-affirming narratives contributed to participants' experience of positive dying, and that reflecting on their strengths and how they had overcome problems in the past helped them to adapt to their illness and enhanced their resilience. In two similar studies, Lindsay collected stories from palliative patients in New Zealand, in his role as their district nurse, and Benzein and Saveman invited couples experiencing home-based palliative care in Sweden to share their stories with nurses. Both studies found that storytelling helped participants unburden themselves, with Lindsay describing this as a "healing experience" (441) for patients and their partners, and reflections also sometimes leading to practical ideas for managing their daily lives. However, Lindqvist et al. introduce a note of caution on the use of storytelling as formalised therapeutic approach. Their investigation of Dignity Therapy in Sweden (which involves the interviewer co-constructing the EoL patient's life story into a written document) found a lack of evidence of benefits for participants, and also problems around the agency of potential participants and the amount of resource required for the therapy.

Focusing on the experiences of patients' relatives, Seal et al. adopted a storytelling approach to explore why ten cancer patients had been unable to fulfill their wish of dying at home, and the impact this had on relatives. Stories told by the deceased person's loved ones highlighted factors preventing continuing care at home, particularly the detrimental impact on

the carer's welfare (especially when they themselves were elderly), and admission to hospital due to a medical emergency. This often resulted in guilt and regret for the carer, for being unable to support their loved one in dying at home. Conversely, the study by Carlander et al. focused on the experiences of ten individuals who had cared for a family member dying of cancer at home. The caregivers had found many challenges in handling everyday life at home with the dying person, and witnessing the dying person's suffering was particularly difficult. Relationships between the caregiver and their relative were stretched by the increased intimacy and lack of privacy, and participants described feelings of anger, insufficiency, boredom, restlessness, and exploitation by other family members, although Carlander et al. also note how the experience enabled caregivers' personal growth.

It is clear from the current literature that making and enacting EoL choices is a difficult process, despite the popularity of this discourse amongst policy makers in England. Therefore, how people actually experience EoL choices may be quite removed from policy expectations. Whilst previous studies have investigated the preferences of people in palliative care at the EoL, and the experiences of caregivers before and after their loved one's death, little is known about how older people engage with making EoL choices in advance of this final stage of life. In light of the potential benefits of storytelling in facilitating communication about EoL issues, we explore here how, and to what extent, does storytelling play a role in making and expressing EoL choices?

Methods

Data was collected as part of a larger project exploring EoL preferences amongst people aged 70 plus, using a qualitative approach to enable in-depth understanding of participants' views. This age range was chosen in order to gain the perspective of older people who could be making EoL choices, in advance of the final stages of life when these plans would be

enacted. Ethical approval for the research was granted by the authors' University ethics committee. Potential interviewees were informed that participation was voluntary, that they had the right to withdraw from the study up to two weeks after the interview took place, and that their data would be anonymised, with nothing reported that could be used to identify an individual. Verbal and written informed consent were gained from all participants before data collection commenced. The fieldwork was carried out by two of the authors, who have extensive experience in qualitative data collection exploring sensitive topics. Data collection took place before the COVID-19 pandemic, so the interviews were not impacted by the restrictions in place during the outbreak. Age was the primary inclusion criteria, with a minimum age of 70, and then quota sampling was used to select participants from within this population based on demographic factors that may intersect with EoL care needs, specifically gender, residential area (suburban or rural), and type of accommodation. The achieved sample is set out in Table 1.

Table 1: Demographics of Achieved Sample

Age	No. of participants
70-79	14
80-89	5
90-99	1
Total	20
Gender	
Male	7
Female	13
Total	20
Area	
Suburban	15
Rural	5
Total	20
Accommodation	
Own/rented home	18
Sheltered accommodation	2
Total	20

Interviewers used a moderator's guide developed from the EoL care and choice literature, to gain insight into participants' views and preferences on EoL issues. Interviews were

conducted by a single interviewer and were carried out in participants' homes, to help them feel at ease. Interviewers began by asking participants about their home, how long they had lived there, and who lived with them, to build a rapport before asking more sensitive questions related to EoL issues. The interviews used open ended questions to elicit in-depth answers from participants, and lasted around 60 minutes. Participants were asked questions about their views and experiences, but were not prompted to tell stories during the interviews, so any stories told by participants arose spontaneously. This conversational interview style provided insight into how participants naturally used stories when discussing EoL issues. All interviews were audio recorded and transcribed, and transcripts uploaded into NVivo 11, in order to facilitate data analysis.

A deductive thematic analysis was carried out by two of the researchers, using a coding manual to guide the analysis. The analysis followed a three stage process; firstly, identifying stories in the data, secondly, coding the content of the stories and the surrounding discussion for EoL issues, and thirdly, identifying themes that linked the coded data in the stories and the surrounding discussion. In order to bring rigour to the identification of stories in the data, we drew upon the narrative literature to define stories as an individual's telling of a set of connected and causally related events, (Bruner; Busselle and Bilandzic; Sturgess; Tomashevsky), organised into a plot, which follows a beginning-middle-end sequence (Booker; Keen), described by Czarniawska (2) as "an original state of affairs, an action or event, and the consequent state of affairs". We developed codes for the second stage of analysis from the EoL literature. The two researchers undertaking the analysis coded the data independently, but met regularly together and with the wider research team, to discuss and agree the coding and themes, in an iterative process involving initial reading of the data, analysis, discussion, reflection, and then further analysis and discussion. This provided consistency in the coding process, between the two coders and within the data, and ensured

that the final themes were closely related to the data. We discuss the findings here, with illustrative examples of the stories told by participants in discussing EoL issues. Pseudonyms have been assigned to protect the anonymity of individuals, but we have included participants' age, to provide a sense of their potential proximity to EoL choices.

Results

Stories were ubiquitous throughout the interviews, with all participants becoming storytellers at some point. We identified a total of 49 stories about EoL issues in the interview data – the majority of these stories focused on caring at the EoL (39 stories), a small number focused on a person's death (4 stories), and some focused on the period after a person's death (6 stories).

Two key EoL choices identified in policy documents are “where” and “who” – where an individual chooses to receive care and eventually die, and who they choose to provide the care. Participants particularly told stories in response to questions about their thoughts on staying in their own home at the EoL versus going into a care home or hospital. They also told stories about their preferences for the type of care they would want to receive, and from whom. These questions gave rise to the greatest uncertainty for interviewees, and storytelling helped them to think through their answers. The setting of each story was therefore recorded as part of the analysis, wherever this was mentioned by the storyteller. EoL experiences recounted in the stories took place in three settings: in hospital (7 stories), in a care home (6 stories), or in the person's own home (21 stories). Fifteen stories did not have a specific location. Care in hospitals and care homes was provided by care and medical professionals, but stories about care at home were divided into those where care was provided by professional carers (9 stories) and those where care was provided by non-professionals e.g. relatives/friends/neighbours (12 stories). Stories were nearly all about the personal

experiences of the storyteller, including their own experiences in receiving care or in caring for someone else at the EoL (20 stories), or the experiences of people they knew, such as relatives, neighbours, friends, or colleagues (26 stories). Just three stories were told where the storyteller had no personal connection with the actors in the story, and instead were a re-telling of a story from a TV report or newspaper article. A summary of the EoL stories told by participants is presented in Table 2.

Table 2: EoL Stories Told By Participants

Story focus	No. of stories
Caring at the EoL	39
Death	4
After death	6
Total	49
Story setting	
Hospital	7
Care home	6
Own home – care provided by professionals	9
Own home – care provided by non-professionals	12
No location specified	15
Total	49
Connection of story to storyteller	
Personal story (storyteller directly involved)	20
Story about a personal contact (relative/friend/neighbour/colleague)	26
No personal connection (story from the media)	3
Total	49

Our analysis explored how stories related to participants' EoL preferences, and we found 25 instances where stories were linked to participants' expressions of their EoL wishes.

We will therefore focus on these stories in the remainder of this paper. The majority of interviewees (18 out of 20) preferred to stay in their own home at the EoL, while one person wanted to move in with their daughter, and one wished to move to sheltered accommodation. Participants used stories in a variety of ways whilst discussing their preferences. Some

participants expressed their preference and then supported this with a story. For example, Malcolm (aged 83) followed the expression of his preference for staying at home with a story about his mother's experience in a care home:

Definitely stay in your own home as long as you can! My mother, she lived to around about 97/98 and she lived in her own home until she was pretty well 90 and then she had a fall and therefore she had to have, you know, at that age it didn't help her so she went into a care home. That finished her off. All she said was "I want to be at home in my own state", and I feel the same way. When I used to visit her, it was very nice there, she had her own little room and everything, meals for her, but you lose all the things that you own, you know, it's not the same. They say you can take your things with you but it's not the same. I can take my armchair but that ain't life is it. I'd sooner die here out in the garden quite honestly.

Similarly, Agnes (aged 70) told a story about caring for her mother to illustrate her preference for staying at home:

There needs to be a lot more help to keep people in their homes I think, because you feel happier in your home. (...) I looked after my mum and she had a bit of dementia and diabetic, and she was quite difficult to look after because she wasn't very accepting of any help with any personal care. She was quite difficult, and I think it was because I was her daughter, and she didn't feel that I should do that. But you know, we got past it in the end and that helped to keep her in her own home.

Despite having experienced difficulties in providing care to her mother, Agnes created a story that made these difficulties worthwhile (by enabling her mother to stay at home), and which aligns with her own EoL preferences. In this way, storytelling was used by participants to explain or justify their expressed preference. Other participants started by telling a story, and then expressed their preference, such as Bob (aged 91):

Bernard our friend, he lost his wife. He lived in a flat, a very nice flat, but it became that he couldn't look after himself and he has gone into a care home. And from what I gather from him he is not very happy (...) Food is not so good. He always had a lady cooking for him and I can imagine it's (not as good). When I see him, I think to myself thank goodness I am not in that position. He is in a home, he is not happy. I don't know why the children put him there in the first place. (...) We are just happy here (at home).

Bob used storytelling here to first share the experience of someone else (in this case a friend), in order to compare this to his own situation, and express his preference to stay at home.

The same preference was expressed by Maureen (aged 72), and the story she tells to follow this shares her own experience of providing care to a neighbour:

It's a good thing (to stay in your own home). (...) When I lived at my other house, I used to have a neighbour right across and I used to go and look after her every day when her husband died, because we were always good neighbours and I used to go over there and kind of keep my eye on her, you know. So I know, she stayed there until she was really poorly.

This story implicitly acknowledges the need for support from others in order to stay at home, although Maureen does not state this outright. The story also ends with the implication that it is not always possible to stay in one's own home when the individual has more serious medical needs, although again Maureen does not explicitly discuss this.

The stories discussed so far have all been aligned with the storyteller's own preferences, but this was not always the case. For example, Irene (aged 74) told a story about a client's experience in a care home:

One of my ladies did end up in a care home which was actually a very nice one. It was a lively, nice place. It was really good and I used to go there, I did her hair for a

bit for her. But they had their own girl going in to do all of them, so I was probably, I needed to get into her room, I was probably a bit of a nuisance. She was fine with it, but it was nice. It was sort of lively, things happening, people doing things. I don't know if it was the layout of the place, but it seemed busy. (...) She could sit by the window, they had a lovely garden. She could sit by the window, that was her spot, see the birds and squirrels and that's what she liked. (...) So it was a good home.

Irene follows this story however by saying "I would prefer to stay at home definitely".

Telling this story presents Irene with a tension between her established view (that staying at home would provide the best EoL experience) and a potentially competing view (that care homes can also provide a positive EoL experience). Irene reconciles this by saying "I suppose a good home like Doris was in, that's fine." In this case, storytelling opened up the possibility of other EoL options for Irene, based on the story she created about the positive experience of someone else.

Some participants used stories to illustrate in which situations their preferences might change and why. Clive (aged 73) expresses his preference to stay at home, but then follows this with a brief story about two friends (whose partners have presumably suffered with a form of dementia):

The one thing I don't want to do is finish off in a home where I am going to vegetate and gradually lose everything. That is a worry. If I had my wish, I would just like to wake up dead as you might say. I think it's a problem, but when I am incapacitated, yes I would like to stay in my home definitely rather than go somewhere else

Now that puts pressure on people around me, that's the problem obviously. (...)

I think if I suddenly went doolally and started to become aggressive and things like that - we have had 2 friends where their partners have become aggressive and they had to put up with them. I think that is very sad because that is not the person they

were, so I think those people have to go into a home because you just can't cope with them quite honestly. But I think if you are mentally fit and reasonably physically able, I am all in favour (of staying at home).

Reflecting on his friends' situation in the story leads Clive to add a caveat to his original preference (that staying at home is preferable as long as you are mentally and physically well). Similarly, Joan (aged 73) tells a story about her father-in-law to explain her preferences in different scenarios:

I suppose it would depend how bad you were. If you could get out of bed to go onto a commode or to go to the bathroom or not, that would be the main thing. (...) I would imagine if you were really bad you would have to go into a home, but I would like to stay here as long as possible. (...) I remember with my father-in-law, he had a stroke and he was incontinent, and when my mother-in-law died, the doctor said, and I said, "We will have to have him with us". He said no, he said he has had his life and he said to see to him toilet wise, because he used to mess himself and that, he said that's not for a daughter-in-law to do. (...) He had to go into a nursing home in the end.

In these cases, storytelling enabled participants to explore the future situations in which they may find themselves in old age, and consider their preferences in light of different health and care needs.

Storytelling sometimes highlighted the conflicts inherent in making EoL choices to the storyteller. The two stories told by Iris (aged 80), her reflections on the stories, and then the expression of her preferences, illustrate this:

Story 1 - My neighbour next door, I mean she has passed away now two years ago, but she was very, very bright. She was getting near her 90s and they kept on and on, "You should have a bit of care", because she was on her own. So, "Oh yeah, all right" she said, but then she had them and they came and it was six o'clock, "Oh we

will put you to bed now”. Well, she was a lady who sat until 11 o’clock at night watching television. And then they would say, “We will help you get up”, because she walked with a stick and that. But normally she got herself up about eight o’clock but “No, we will come get you up”. But she said 10 o’clock she was still sat in bed waiting. So she got rid of them. So to me that wasn’t good. (...) I wouldn’t have them come here and tell me I had to go to bed at 7 o’clock, You know. So carers, no, I wouldn’t.

Story 2 - My mother was a nurse all her life. We lost her five years ago, she was 97 but right until she was 85/86 was absolutely marvellous. Walked from Kingswood up to Soundwell with her little dog. Lived on her own, very independent, a bit like me really. And then all of a sudden she went down with dementia and then she had to go into a home. It was the hardest thing. My younger sister nursed her for, it must have been five years, and we all took turns. She knew us but it was very difficult. (...) People don’t want to leave their home and go away. I mean, I shudder at the thought of a home. I mean, if I couldn’t manage, I would only be too pleased for somebody to come in and help me to stay, but not put me to bed at seven o’clock.

We can see here how Iris changes her mind about having carers support her in living in her own home. Telling the story about her mother reminds Iris that she feels it is preferable to stay at home rather than go into a care home, and she would be willing to have carers come into her home to enable her to do this. The tension remains though that she would want to retain control of her daily schedule, when the previous story has already illustrated that this may not be possible. Some participants had stronger reservations about the practicalities of staying at home, for example, Brian (aged 76):

It would be good news to stay in your own home as long as you can with the right support but it’s more and more difficult to get that I think. We have got a friend just

gone in, she's 90 something, just gone into a home. She lived across the road there.

Doesn't want to do that but she just couldn't get the sort of privatised support. She got a different person all the time and she used to get a bit stroppy about it. And they didn't come until 11 or something. She always used to be up waiting for them, already dressed.

Ian (aged 70) was one of the few participants who re-told a story from the media, and this expressed similar concerns about the ability to stay in one's own home:

The news at the moment that the hospital beds, there's not enough of them. Older people are in hospital at the moment, there is a lady who has been in hospital two months and she is perfectly able to go home but she needs carers at home and local councils haven't got that sorted out. So there is no carers at home for her, so she is stuck in hospital. Yes so I am quite in favour of that (remaining at home) but I think the councils need to sort it out.

In both Brian and Ian's cases, they used storytelling to illustrate their understanding of the difficulties in enacting their EoL preferences and temper their expectations that these preferences could be realised.

Discussion

Our analysis has illuminated the multiple ways in which storytelling can play a role in making and expressing EoL choices, and adds to our understanding of how people engage with making EoL choices. We can summarise the ways in which participants used stories in the context of EoL choice making as follows:

To make sense of EoL experiences and form their EoL preferences. Individuals told stories about the EoL experiences of relatives, friends, and neighbours, reflected on these stories, and used these reflections to determine their own EoL preferences. This is supported in the

narrative literature, as it is well established that individuals can effectively make sense of their world through constructing stories (Bailey). Bruner proposes that humans are pre-disposed to organize experience into a narrative form, and McGeough describes how storytelling provides a way for the teller to order past experiences, and then reflect on and make sense of these experiences. Previous studies on EoL issues by Baydala et al., Benzein and Saveman, and de Jong and Clarke, all found that storytelling helps tellers to create meaning from story events. In particular, we found that individuals' stories about their relatives' and friends' experiences in care homes were often followed by an expression of their own preference for staying at home. Care homes were generally seen as a last resort for when an individual could no longer remain in their home, and a poor substitute for an individual's own home. This echoes Andrews and Beer, who note the "low expectations" in the care of older people within care homes.

To add detail to and justify their EoL preferences. Some storytellers expressed their EoL preferences, then used storytelling to elaborate on these. This supports Chan and Pang, who found that telling stories helped nursing home residents to clarify and communicate their treatment preferences. Stories also enabled interviewees to justify these preferences, to both themselves and the interviewer, explaining why they had opted for a particular choice, based on their own and others' experiences. This role of storytelling in creating emergent understanding is noted by Benzein and Saveman, who found that telling stories about their illness enabled individuals to put their thoughts and feelings into words, and that the process of constructing stories helped individuals to learn from these.

To consider multiple EoL scenarios and preferences. We saw storytellers express their EoL preferences, follow this with a story, and then return to add a caveat to their preference, or even express a different preference. Stories are acknowledged to help tellers consider multiple perspectives on past, present, and possible future events (Herman), and work

through problems (Abbott). We saw this particularly where participants wanted to stay at home for their EoL, but then told stories about experiences that made this difficult or impossible (for example, certain medical conditions or incontinence), and considered how their own preferences would change in these situations (such as wishing to go into a care home instead). This follows Cox et al., who note that concerns about the nature of dying and being a burden to others affects individuals' preferences for their care and place of death. The relational nature of EoL choices, and the dependency on others to enact these choices, is highlighted here, and can cause tension for many people. This illustrates particular cultural values around EoL, with autonomy and control central to quality of life, which may vary between individuals and cultural contexts. Frank (30) also notes this, commenting that "people define themselves in terms of their body's varying capacity for control...some ill people adapt to these contingencies easily: others experience a crisis of control". Storytelling here made these concerns and values explicit for participants, and opened up other EoL choices, sometimes resulting in them amending, or changing, their preferences.

To manage their expectations about achieving their EoL preferences. Several participants expressed their EoL preference, then followed this with a story that demonstrated their awareness of the difficulties in achieving this preference in reality. Although the majority of participants in our study wished to spend their EoL at home (as in previous studies by Bone et al. and Fleming et al.), stories illustrated the challenges in enacting this preference, including the availability of carers to provide high quality and timely care, and the burden placed on relatives to meet the individual's medical and personal needs. This builds on the concerns expressed by Borgstrom and Walter that although EoL choices are framed in policy rhetoric as an individual decision, they often have implications and repercussions for relatives, as well as requiring resources and support from other institutions, inviting the need for a more relational view of EoL issues.

Participants in our study told stories about EoL issues without being prompted, perhaps because the exploratory, in-depth nature of our interviews gave them the space to feel comfortable doing so. Other situations where it may be desirable to discuss with people their EoL preferences may be less conducive to storytelling, for example in appointments with doctors, nurses, or other health and care professionals. Community based doctors in England (known as General Practitioners, or GPs) have been encouraged to make care plans with their patients approaching the EoL (Hamilton), and Boyd and Murray argue for open, early discussions between patients and doctors about what matters to a person at the EoL. However, appointments with doctors tend to be time limited and focused on immediate health issues, and studies have reported difficulties for GPs in initiating these conversations and helping their patients to make care plans (Scholten et al.; Wichmann et al.). Our research supports the findings by Chan and Pang, and Southall on the value of using a storytelling approach to communicate EoL treatment preferences, and we therefore suggest that GPs and other health and care professionals need to facilitate appropriate space for discussions about EoL preferences with patients, and would benefit from encouraging patients to share and reflect on stories about EoL experiences. Sudore and Fried make a case that advance care planning between clinicians and patients should focus on preparing individuals for the different types of decisions and conflicts they may face at the end of life, and storytelling could again be a valuable way of exploring these possible scenarios, and helping to ensure people receive treatment and care at the EoL in line with their “values, goals and preferences” (Sudore et al.). Similarly, Costello notes that planning for the EoL can make this a less lonely and stressful experience for the dying person and their loved ones. Family members, friends, or individuals themselves who want to open up discussions about EoL preferences may find that sharing stories about EoL experiences and reflecting on these together, helps to explore people’s wishes, and what is needed to enable these. In both

situations, the role of the listener is crucial, as noted by authors including de Jong and Clarke, and Terkildsen and Wittrup, with the active interchange between storyteller and receiver helping the teller to construct and reflect upon stories, and enabling the creation of meaning.

This study has focused on the experiences and preferences of individuals aged 70 plus in England, and their stories reflect the health and social care structures and norms in this country. As acknowledged by Cox et al., attitudes towards EoL issues are likely to be affected by the varying healthcare systems in different countries. Further research exploring EoL choices in countries with different healthcare systems and approaches to EoL care would be valuable to provide insight into how other cultures make and enact EoL choices, and the role of storytelling in this process.

Our research has found that storytelling allows people to make sense of and reflect on previous EoL experiences, and form, elaborate on, and justify their own EoL preferences. Stories also bring to the fore the difficulty in making EoL choices, when it is impossible for most people to predict their future physical and mental health, and where choices are dependent on resources provided both within families, and within health and social care systems. This can make it challenging, and often impossible, to enact people's choices. Many people are aware of these uncertainties, and storytelling can help people to explore multiple possibilities for their EoL, and reconcile them to care options which may be preferable in different scenarios. This also has implications for policy in England on EoL care, suggesting that the focus on individual choice may be unhelpful, when in reality choices for many are limited, and constrained by factors beyond their control.

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