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# Talking about death and dying: Findings from deliberative discussion groups with members of the public

Eleanor Wilson , Glenys Caswell , Nicola Turner  and Kristian Pollock 

NCARE, School of Health Sciences, University of Nottingham, Nottingham, UK

## ABSTRACT

Talking about death and dying is promoted in UK health policy and practice, from a perception that to do so encourages people to plan for their end of life and so increase their likelihood of experiencing a good death. This encouragement occurs alongside a belief that members of the public are reluctant to talk about death, although surveys suggest this is not the case. This paper describes findings from a research study in which people participated in deliberative discussion groups during which they talked about a range of topics related to death, including talking about death, the good death, choice and planning and compassionate communities. Here we report what they had to say in relation to talking about death and dying. We identified three themes: 1. The difference between talking about death as an abstract concept and confronting the certainty of death, 2. how death and dying presents issues for planning and responsibility, and 3. approaches to normalising death within society. For our participants, planning was considered most appropriate in relation to wills and funerals, while dying was considered too unpredictable to be easy to plan for; they had complex ideas about the value of talking about death and dying.

## KEYWORDS

Deliberative discussion groups; denial of death; normalising death talk; planning for death; talking about death and dying

## Background

Current policy for end-of-life care incorporates a core assumption that encouraging the public to talk more openly about death and dying will result in increased uptake of Advance Care Planning (ACP) (Department of Health, 2008). This provides a means for individuals to reflect on, discuss and document their preferences for future care at the end of life and to direct decisions about care and treatment in the event of lost capacity (Sudore et al., 2017). Increased take up of ACP is expected to improve the quality and experience of end-of-life care for patients and their families as well as reducing costs of health care (Brinkman-Stoppelenburg et al., 2014; Department of Health, 2008; Fleuren et al., 2020). Alongside policy, the notion that the general public in the UK and other Western developed nations, is ‘death denying’, and that death is a ‘taboo’ topic which people shy away from talking about, remains part of the national zeitgeist (Cox et al., 2013; Kirshbaum et al., 2011; Tradii & Robert, 2019; Troyer, 2014; Zimmermann & Rodin, 2004; Zimmermann, 2007). Promotion of ‘death talk’ continues to be

**CONTACT** Eleanor Wilson  [eleanor.wilson@nottingham.ac.uk](mailto:eleanor.wilson@nottingham.ac.uk)  NCARE, School of Health Sciences, University of Nottingham, Nottingham, UK

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the focus of various campaigns and a proliferation of resources encouraging the public to talk about death and dying (Co-op Funeral Care, 2018; Death Cafe, 2021; Dying Matters, 2016; Gawande, 2015; Hebb, 2018; Macmillan Cancer Support, 2017; Manix, 2017; Marie Curie Cancer Care, 2014; Royal London, 2021). Such initiatives stem from the position that public unwillingness to engage in ‘death talk’ is in some way problematic, constituting a form of denial which directly impedes the individual’s capacity to achieve ‘the good death’ through the exercise of informed choice and forward planning (Zimmermann & Rodin, 2004; Zimmermann, 2007). Dying well is characterised as involving awareness, being at home, in the company of loved ones, and having rejected heroic or active future treatment (Department of Health, 2008). The discourse of ‘the good death’ also places constraints on *how* death can be talked about. The death positivity movement does not encourage talk about options such as sudden death, suicide, or assisted dying (DeVeney Incorvaia, 2020; Koksvik, 2020). Alternatives to the positive, planned, ‘home’ death become marginalised by this narrative and are rarely discussed as valid options or choices (Pollock & Seymour, 2018; Pollock, 2015). Despite representations of death denial as a modern, contemporary problem, it is notable that similar ideas have been expressed over the past 50 years notwithstanding a continuing lack of supporting evidence (Lofland, 1978; Robert & Tradii, 2019; Tradii & Robert, 2019; Troyer, 2019; Zimmermann, 2007).

Healthcare policy and planning have embraced the drive to encourage talking about death as a way to facilitate and direct a ‘national conversation’ about death and dying (Kellehear, 2013). The End-of-Life Care Strategy (Department of Health, 2008) identified

*the lack of open discussion between health and social care staff and those approaching the end of life and those who care for them, as one of the key barriers to the delivery of good end of life care. (Department of Health, 2008, p. 50)*

Talking is considered a prerequisite to planning and preparing. A planned death enables healthcare services to flex to meet patient preferences and achieve ‘the good death’ (The Gold Standards Framework, 2018). However, UK policy that all health care workers should be able and willing to engage in ‘difficult conversations’ about goals of care with dying patients has not been accompanied by dedicated funding or training resources to support this endeavour. Healthcare professionals find it difficult to initiate discussion of ACP and the take up of such planning within the population remains low (Almack et al., 2012; Lewis et al., 2016; NICE, 2015; Pollock & Wilson, 2015; Rietjens et al., 2016). Many of the major charities in the UK provide resources for those with life limiting diagnoses and/or in older age (for example: AgeUK, Macmillan, Marie Curie, British Heart Foundation, Motor Neurone Disease Association) aimed at fostering discussions between family members, and sometimes encouraging them to explore and express their wishes with healthcare professionals. Macmillan’s report entitled ‘No regrets: How talking more openly about death could help people die well’ frames this as ‘By putting plans in place earlier, and thinking about what matters to you and your family, it may be possible to die “well”, and in the place of your choosing’. (Macmillan Cancer Support, 2017, p. 4). There also continues to be a rapid increase in grassroots public initiatives such as Death Cafes (<https://deathcafe.com/>), death festivals (<https://deathfest.co.uk/>, <https://kickingthebucket.co.uk/>) and, The Death Positive Movement (<http://www.orderofthegooddeath.com/>). The upshot of the death positive movement is that dying well is presented as achievable and even an entitlement, and the ‘bad death’ is seen as avoidable, provided

individuals are prepared to talk and plan (Co-op Funeral Care, 2018; Macmillan Cancer Support, 2017; Royal London, 2021). However, this ideological position lacks acknowledgement or engagement with the negative or difficult existential aspects of dying, of suffering, uncertainty, grief and loss, and the mental and physical impacts of long, drawn out, dying (Almack, 2019; Aoun et al., 2021; Vig & Pearlman, 2004; Wilson et al., 2021).

The assertion that people do not to discuss death and that it is a 'taboo' (Co-op Funeral Care, 2018; Macmillan Cancer Support, 2017) has not been established by research evidence. UK surveys report that approximately 70% of people *are* comfortable talking about death and dying (British Social Attitudes, 2012; ComRes, 2016; Jameson, 2021). Findings of several studies suggest that talking about death is avoided because of perceptions that *others* may be uncomfortable, rather than the individuals themselves (British Social Attitudes, 2012; ComRes, 2016; Islam et al., 2021; Macmillan Cancer Support, 2017). Overall, these findings suggest that the 'taboo' against death talk may be more perceived than real (Miller-Lewis et al., 2021), and that its function within the different strands of the death positivity movement are primarily ideological (Lofland, 1978). End of life care policy has been formulated with remarkably little public consultation while little research has been conducted into public attitudes to death and dying (Cox et al., 2013; Islam et al., 2021).

This article reports findings from a qualitative study using deliberative discussion groups to engage members of the public in conversations about death and dying in the UK. Its aim is to extend the currently limited knowledge of public understanding, preferences and concerns about talking about death and dying. This should be central to the development of end-of-life care policy and the development of responsive and culturally appropriate services for dying persons and their families.

## Study design

The deliberative discussion groups were part of a wider study that included the perspectives of bereaved people and patients at the end of their lives gathered using online and telephone qualitative interviews. The groups were designed to bring the public into the project in such a way that they would have the opportunity to express their views and discuss them with others. The ethos behind deliberative discussion groups is that with each session participants increase their knowledge and familiarity with a topic. They have time to reflect on their own views and those of the group during the research process. Thus, over the course of the sessions, their views become increasingly informed, rather than, cross-sectional responses which are likely to be elicited by survey questions or single interviews (Rothwell, Anderson and Botkin, 2016).

## Recruitment

Each group was composed of members of the public who were recruited by advertising in various ways to try and gain as diverse a sample of the population as possible. Online, we used Twitter, Facebook, Call for Participants and our own study website. We placed adverts in community newsletters and magazines in the East Midlands area as well as via Help the Hospices, Marie Curie and Public Face. The University of Nottingham also issued a press release. Organisations such as Compassion in Dying and Help the Hospices publicised the

study in their own newsletters. Direct contact was made with the Faculty of Medicine's Public Engagement Group as well as a range of organisations, including businesses, community and sports groups. Individuals who were not able to attend a scheduled discussion group were offered the option of taking part in a single one-to-one interview over the telephone or online, to discuss the topics covered in the deliberative discussion groups.

### ***Data collection***

Before each session a small number of resources were circulated to participants via email as a spur to thought and to introduce alternative viewpoints. These were relevant to the topic under discussion, and were made up of reading materials, and short podcasts or videos. Engaging with the materials was optional, but most participants chose to do so to some extent. Videos proved to be popular as participants found these accessible and easier to digest than written text. Each session began by asking if participants had any thoughts or comments about the materials.

Across the four sessions different topics related to death and dying were covered. These were:

- Talking about death and dying
- The good death; dying well
- Choice and future planning
- Compassionate communities

There was considerable crossover of topics and participants often referred back to previous discussions. Sessions were guided by the researchers, using broad questions to encourage conversation and to engage each of the participants as much as they wished. All group sessions were audio recorded using external devices. Consent was documented by post or email and confirmed verbally at the beginning of each session. Participants were informed when recording was started and stopped.

### ***Adjustments due to Covid-19***

The intention was to run five different groups of up to ten people, meeting once a month for four sessions of up to two hours. The first two groups met for their first session during the second week of March 2020. However, following the UK government's institution of a national lockdown to contain the Covid-19 pandemic from March 23rd, all in-person sessions were cancelled. The deliberative discussion groups were moved to an online, secure, video chat platform.

Given the move to online data collection we adjusted the study design to increase the number of groups to seven and reduce the number of participants per group to approximately four. We also reduced the length of the groups from two hours to one hour. Each group still took part in four sessions, which were held weekly rather than monthly to maintain momentum and in response to participants' preference.

## Analysis

Thematic analysis was approached as an iterative process (Braun & Clarke, 2019). After each group session the researchers undertook a debriefing to discuss the ideas raised by the participants (Bazeley, 2021). All audio recordings were transcribed, transcripts anonymised and uploaded to Nvivo12©. All four sessions in the first deliberative discussion group were read and coded by KP, GC and EW to establish a basis for a coding framework and key themes. Between the four members of the study team (KP, GC, EW and NT) all further transcripts were double coded over a period of six months. Throughout this time the nodes within NVivo were discussed, reviewed and revised a number of times in order to gain clarity and consensus (Jackson & Bazeley, 2019). Extensive coding notes were kept and memos were used to record and explore nodes.

## Ethics

Ethical approval for the study was given by the University of Nottingham Faculty of Medicine and Health Sciences in October 2019, REC reference 385–1909.

## Findings

Seven deliberative discussion groups and five individual interviews were completed between March 2020 and February 2021. Two individual interviews took place over the telephone, and three using an online video platform. In total 41 people were recruited. Table 1 shows participant demographics. The majority of participants were female (78%) and highly educated: 71% to at least degree level. While we had an age range of 30–81, and a third of participants were under 50, only eight were under 40 (20%).

The focus group discussions explored participants' motivations for talking about death and why it might be considered 'good to talk'. Three key themes were identified: 1. The difference between talking about death as an abstract concept and confronting the certainty of death, 2. how death and dying presents issues for planning and responsibility, and 3. approaches to normalising death within society. Each of these themes is presented below and illustrated using extracts from the data (see Table 2 for a key to participant identification codes).

**Table 1.** Participant demographics.

Total no. of participants n=41	Deliberative discussion group participants n=36		Individual interviews n=5	
	Age Range: 36-81 yrs Identified gender	30-49 yrs n = 15 (34%) Female n = 32	50-69 yrs n = 16 (39%)	Male n = 9
Marital status	Single n = 4	Married /Partner n = 22	Divorced/ Separated n = 12	Widowed Not known n = 2    n = 1
Education	Secondary n = 7	Tertiary n = 29	Not Known n = 5	

**Table 2.** Key to participant identification codes.

DDG1(1)	DDG = Deliberative Discussion group. The first number is the Group number (eg 1-7), the number in brackets denotes the session number (eg 1-4)
DGInt	Interview covering discussion group topics for those unable to attend groups
F3	Female participant The number shows which female participant is talking
M1	Male participant The number shows which male participant is talking
...	Three dots are used when some text has been removed for clarity and to condense the quotation.

Some extracts from the DDGs are presented in a turn taking, conversational format to be as representative of the course of the discussion as possible. Other extracts are the comments of one individual from the group.

### **The abstract and the certain death**

Participants recognised a contrast between the abstract nature of talking about death when it was not an impending or personal issue and consideration of the certainty and inevitability of death of oneself or others.

*... it's relatively easy to talk about things that are hypothetical, isn't it, it's when you're actually faced with somebody who's dying and perhaps you haven't talked about those things before, then it's really much more difficult to say, 'Well, where do you want to be buried, or do you want to be cremated?' That's just a hard thing to do, isn't it? (DDG2(1))*

Most recognised that talking about dying and death should be a personal choice and that 'blanket' approaches which put pressure on people to talk would not be appropriate, and certainly not before they were ready and willing to do so. Some reported that talking about death as a hypothetical or distant event could make it easier. For example, many talked about how they had engaged in some conversation with partners and family members when planning a will. A key time to talk about dying and death was seen as when there is a tangible need, such as when someone in the family is facing a terminal diagnosis. It was also recognised that while making the conversation more necessary, the concrete certainty of death could cause those not wanting to talk to shut down further. Talking was recognised as a two-way interaction and most reported instances when family members had been unable to engage with these kinds of conversations.

*I've tried several times to talk to my youngest son about it, and basically, it's fingers in the ears, la-la-la-la-la-la, you're never going to die. ... So I never actually manage to move forward with that. I've got songs I want playing at my funeral, things like that, and I want to talk about my financial affairs and those sorts of things, but basically he makes it very, very clear that he doesn't want to discuss it. (DDG3(1))*

*F1: ... my five-year prognosis was very poor. ... my parents were like 'Oh, we don't want to know ... of course you won't die, you'll be fine'. ... And, no they wouldn't speak to me about it. ... I thought they would talk it through with me.*

*F5: They're in denial.*

*F2: That's their own fear, isn't it?*

*F5: If they don't talk about it maybe it's not real. (DDG1(1))*

With no personal connection to dying or death, the need to address the issue can easily be masked by every day busy-ness and a focus on the 'now'. Participants also referred to 'tempting fate' and how a general fear of death might hinder people talking openly.

*But it might be years . . . one can see it's a common sense point of view. I mean why would you think about it when you're younger unless one of your relatives dies and you start to think about it. And, what I've encountered in my life is that even with older people when I start to talk about it they look very uncomfortable and say, 'Oh, why don't you just get on with living now? Why go on thinking about that?, I'm too busy enjoying life day to day, I'm not going to even think about it now'. (DDG3(1))*

*I think it helps because then people will gradually get used to the idea. I mean the old fashioned view of 'Oh no, don't talk about that' is not very helpful in my view. Because when something does happen nobody's made any preparations mentally for it. I mean my sister's a classic example. She won't even make a will because she says it's tempting fate. (DGInt02)*

Some felt there were generational and potentially cultural issues that affected the way and the extent to which death and dying are talked about.

*I didn't grow up in the UK . . . it was a surprise to me the unwillingness to talk about death is here as well, because in [my country] I think it's even more so. (DGInt05)*

*But from my husband's side of the family, when it comes to the funeral it lasts for 100 days and there's lots of things that we have to do each day to make sure the passing of the individual is done correctly. . . . Death is a celebration for my husband's side of the family, where it's really upsetting at my side so we don't talk about it. (DDG7(1))*

Some participants mentioned not needing to talk about death. Within close families there might be a tacit understanding of what another person wants, or individuals may be happy to leave decisions about their death to trusted family members or friends. However, the consequences of not wanting or refusing to talk about dying and death were also highlighted. Some recounted experiences of regret and guilt about not knowing whether wishes had been fulfilled. For others there was sadness that key things had not been said.

*People, they equate death with that upset and so they don't want to think about it and they only generally do think about it when there is a death to deal with and then it compounds the stress that people are going through, because then it becomes this pressure to do the right thing by the person who's died and what did they want and there's this guilt that if you don't know what they wanted or if you do the wrong thing (DDG4(1))*

### **Taking responsibility and making plans**

Talking about death and dying was equated with planning and making wishes known. Friends, and especially family members, were considered to be natural confidantes. Healthcare professionals and religious figures were rarely mentioned. Group discussions primarily focused on after the death, with funerals and wills often referenced as conduits for planning. When considering their own death, participants placed little emphasis on wishes for future treatment other than pain management. There was little focus on planning for the end-of-life as this was intrinsically uncertain and too difficult to anticipate or control.

*And you could actually question what's the point? Because . . . I might not be in control anyway, it might be taken out of my control. Who's to say that if I say, 'I want this', it's actually going to work out that way? (DDG5(1))*

Making plans for death was equated with shifting the burden of decision making from family members.

*My mum is nearly 80 and has talked very openly with me about her end-of-life plans and has filled in a [Do Not Resuscitate] form in what circumstances she wants that to be used. But my mother-in-law has advanced dementia and she's been in care . . . my husband has found it very difficult to make a decision about when treatment would be implemented and not . . . there'd been no discussion about it, about death in any circumstance really. So that's been very difficult. (DDG3(1))*

*If I got sort of a major stroke for example and I was going to be a cabbage for the rest of my life I want the plug pulled. [My wife and I] discussed this. We both think the same thing. We've discussed it with all our children and it's now in writing. . . . we have made a decision they will just have to carry it out . . . It's helpful for them in the sense that they know exactly what we feel and because this has been signed and handed over to the medicks there's a medical perspective which is in place already. (DGInt02)*

Lack of understanding of peoples' wishes due to limited discussions of death and dying also formulated further debate within groups about talking as a responsibility. The participant below expresses anger at her father for forcing the family to make difficult decisions about his care.

*So, I would have liked to know more. . . . what my dad had in mind, what he wanted. Because there was one point where he didn't want to go to hospital . . . I was just thinking why he didn't want to go to the hospital. . . . I would have liked to know, to have had that discussion before, before him getting really ill, and almost I'd say dumping the responsibility on the family of either calling an ambulance or not . . . And there were some other big decisions towards the end of his life that were his, but that he didn't own I would say. (DGInt04)*

Yet others were more accepting, and recognised the challenges of talking about end-of-life care with loved ones:

*F5: . . . same with my mum just before she passed away in hospital and I spent many hours with her in hospital, all she said was 'I'm sorry'. And we never had a conversation either about it at all, it was just too painful, but that was I think us as a family.*

*F1: So you didn't try or did you not want to try, because you didn't want to upset her?*

*F5: I didn't want to push her, no, if that's all she wanted to say then I left it at that. (DDG1(1))*

Discussions often touched on when these kinds of conversations would take place and what they might entail. A strong element of this theme was that a trigger or prompt was needed to initiate death talk. This might take a variety of forms, for example, the illness or death of a family member or friend, or the death of celebrity, or character in a television series or film, and older age. In some instances the COVID-19 pandemic was also cited as something that opened a conversation.

*I think you only really talk about it when you have to, and I've had three main occasions in my life when I've had to think about it . . . You're confronted with it, you have to talk about it, and then after a while as time passes you almost revert back to how most people are, which is that reluctance to talk about it. (DDG6(1))*



*We're in our 80s. Our children are, well pushing 60 anyway. . . . We've talked about decisions to be made if we become severely incapacitated and so on and so forth so it's a pretty open book as far as this family is concerned. . . . [and] this coronavirus situation my wife and myself have talked about it quite a lot because she's obviously got [cancer and] practically no immune system and if she gets it, it's very likely the end of the road and probably me the same. (DGInt02)*

There was little recognition of the drive towards initiating a 'national conversation' and while people identified talking about death and dying as a good thing, they didn't always know what it was they should be talking about. One group discussed the separation between what they referred to as the 'hardware' ie the practical side, and the 'software' i.e. the emotional side of death. They felt that making funeral plans was easier as it tended to draw more on the hardware/practical side whereas discussing dying itself would be harder as it would involve tapping into that more soft/emotional side to talking. Many felt they had limited understanding of both these aspects as well as the physical process of dying itself.

*Because broadly speaking most people have been taken aback by what actually happens when people die. We don't know. I still don't know. Unless you are actually a health professional who is there when people die, you tend not to know what happens. It's not like the telly and it's not like the films. We don't have enough information to know how we want to die. (DDG3(1))*

*It's all right encouraging discussion, but they need to give some of the answers as well, like helping people, how they do end of life plans. And that doesn't seem to be being encouraged or advertised, it's just the let's talk about it, but then not what you do about it. (DDG2(1))*

### **Normalisation of death**

Groups discussed approaches to re-integrating death as a part of everyday life and how it might be 'normalised'. A key theme was that our exposure to death in real life has been replaced with 'on screen' deaths, and that rarely did the two correspond. However, social media has opened new avenues of global communication. Discussions centred on death as more prevalent in the earlier part of the 20<sup>th</sup> Century, yet like many elements of life it was less visible and not discussed. A couple of the groups had discussions about how our ability to talk about death and dying has changed over time. This was seen to be in line with general societal progression on openness around complex, difficult and so called 'taboo' topics, such as sex, religion and mental health.

*I think it just falls into the general evolution of our society where people do talk about everything. We talk about sex that we never used to talk about, we talk about religion that we never used to talk about, we talk about our feelings that we never used to talk about. So, it's just in that same genre, isn't it? (DDG1(4))*

Participants also commented on the assumed invincibility of youth presenting no need to talk about death and dying. With the move to a more medicalised model of healthcare and an ageing population, there was a perception that younger people had little contact with the reality of death. Many of the older participants felt their experiences of death had allowed them to be more comfortable talking about it.

*Most of the people I'm socialising with . . . have witnessed their own parents die or relatives of theirs quite recently die, and they all know what they don't want to happen, which then leads*

*into all sorts of other instruments like Lasting Power of Attorney and Advance Decisions and so forth. (DDG3(1))*

Some felt that humour was a useful tool for talking about death and dying and that a light hearted approach was engaging and could strip away some of the fear surrounding the topic. In normalising death and bringing it into our 'everyday' conversation participants felt we would be better equipped to deal with loss more effectively. Educating children was often referred to as the key to normalising death and in turn building this more resilient society with less discomfort about talking about death.

*And I don't have a will in place . . . that's why I do think we should talk about it more because you don't, I just can't imagine how they would feel if something happened to me and I had left [the children] totally unprepared, because there is no other element in their life where I leave them unprepared or unskilled for a situation, so why would I do it with the thing that will have the most fundamental impact on their life? (DDG6(1))*

While participants reported a need to be cautious about causing discomfort by talking about death and dying, many thought that it may be less 'taboo' than anticipated, indeed people may even feel pleased to talk about the topic.

*But I think maybe, I've had the impression that when people [do] talk about it, in the sense that maybe I thought, then many might just feel relieved actually and happy to talk about it. . . . sometimes I also found that when I start talking about it, other people feel free to talk about it themselves, and it feels like they're glad to do so. (DGInt03)*

In their final sessions groups were encouraged to reflect on their discussion and explore whether their attitudes had changed over the period of participation. Many expressed having enjoyed taking part in the group, and while their perspectives may not have changed, they had been broadened by the differing views and reading materials which had been shared. Group 1 reflected on how talking about death and dying may incrementally shift to break down remaining 'taboos':

*F5: I just think anything that can be done to destigmatise it as a conversation just eases the way, unlocks all those tensions and negativities about it and get people talking. . . .*

*F2: I still find when I tell people about our group and what it covers I'm still encountering eyebrow raising and they say 'what on earth do you want to talk about that for, that's just so depressing', and they find it quite odd. . . .*

*F5: They might go away and think about it though, [name], mightn't they, because you've had the courage to share it with them. You have broken a little boundary there, you have gone over a little, you've had a little breakthrough just by even having that conversation. (DDG1(4))*

## Discussion

We identified three central themes around talking about death and dying from the deliberative discussion groups. The distinction between death as abstract and as a present reality was discussed by participants as they explored how, when and whom they might talk to about death and dying. Rather than furthering or protecting their own interests, consideration of *why* they might need to talk about death and dying centred on the desire to plan for after their death and to relieve family members of burden and

decision-making responsibility. The third theme drawn from the data explores if and how we might normalise death in order to allow people to feel more comfortable talking about it and experiencing loss.

Findings show that the concept of death as a ‘taboo’ did not resonate with participants and is more nuanced than portrayed in attempts to generate a public conversation about death and dying. We have illustrated that there are differences between willingness to talk about death per se and being willing to talk about one’s own or a loved one’s death, and between discussing the hypothetical, and talking with someone about their imminent, certain death. A key disparity should also be noted between *thinking* about death and *talking* about death. We suggest these nuances are not captured by the kinds of language used to drive the premise of ‘the national conversation’. Participants in our study recognised that they were generally being urged to talk about death but were not clear what exactly they were supposed to talk about and few reported having encountered conventional death positivity marketing. Those who had engaged in conversations about death and dying reported a focus on practical planning and the management of responsibility for other people’s convenience and wellbeing, rather than the personal pursuit of ‘a good death’. Discussion was primarily with family members and there were few references to planning for healthcare or discussion of any sort with healthcare professionals (Musa et al., 2015). This was presented as more likely to be relevant to older participants as they had experienced a larger number of deaths and were more likely to contemplate their own mortality due to their age.

People’s concerns were often for others’ welfare and benefit rather than their own. Hence failure to plan and communicate wishes was considered to place burden on others. A strong theme focused on discussing arrangements after a death such as wills or funerals and this is reflected in national statistics on the number of people that have wills but do not have other forms of ACP (Samsi & Manthorpe, 2011). Statistics suggest just under half of UK adults have a valid will in place, although the pandemic year in 2020 saw a 76% spike in requests for wills, the focus being on financial planning for after death (The Gazette: Official public record, 2020). The uptake of any form of care planning remains low (Knight et al., 2020). Participants in our study considered dying to be too unpredictable to plan for. They recognised they had a very limited understanding of the ‘options’ at the end of life and knew little about the physical processes of dying (Fleming et al., 2016). A fear of this unknown has been identified as one of the key public concerns about dying (Cox et al., 2013; Islam et al., 2021). While our participants were willing to engage with the ‘big conversation’ (Dying Matters, 2016) as an idea, their agenda for death talk did not align with that of the key stakeholders in talking about death in order to plan end of life care (eg. Dying Matters, Macmillan Cancer Support, Marie Curie, Co-op Funeral Care).

A conversation based on the premise that talking is good leaves little room for those who do not want to talk about death and dying or who do not feel that it is necessary. Our participants generally seemed willing to embrace the notion that ‘talking about death is good’ but recognised the individual and relational nature of talking. Taking into account who they were talking to, and whose death was to be discussed, they acknowledged that there would be times, places and certain people with whom this would not be the case. They also expressed a need for greater normalisation of death in order to reclaim the language and emotional understanding of death, rather than having this shaped for them (Islam et al., 2021). Discussions centred on how death can become

normalised through experiencing deaths of family and friends as we age, the use of humour, and education from childhood. Some participants also noted that taking part in the research had given them the opportunity to talk about something they are rarely able to discuss within social situations. It was highlighted that death cannot be talked about routinely but requires some sort of 'trigger'. This may be the death of someone close, a diagnosis of a serious illness (Samsi & Manthorpe, 2011), media coverage such as an episode of a drama or soap opera, or worldwide deaths such as during the pandemic (Islam et al., 2021; Jameson, 2021). While no one reported experience of someone dying from Covid-19 there were references to the number of deaths this had caused and this prompted some discussions around the uncertainty of life and when to talk to family members about death.

The death positivity movement asserts that there is a problem, i.e. that death is a taboo, that death denial is directly inimical to achieving the 'good death' and access to palliative care, and hence that talking provides the solution to this problem (Lofland, 1978). Yet to maintain impetus it also constructs and reinforces the 'problem' by continuing to emphasise and proclaim that it exists despite evidence to the contrary (Lofland, 1978; Tradii & Robert, 2019; Zimmermann, 2007). The durability of the 'death taboo' construct, and the momentum maintained by disparate interest groups over a period of approximately 50 years is striking and, on the face of it, somewhat surprising. In the process of providing the 'solution' to an assumed problem, a particular cultural script has developed, concerning where and how people should die, who should be with them, and the nature and limits of professional intervention and control (Zimmermann & Rodin, 2004). A specific vision of 'the good death' has become normative within policy and professional practice, so people who wish to have a different experience (e.g. assisted dying (Lee, 2010), dying alone (Turner & Caswell, 2020), dying in hospital (Pollock, 2015)) are marginalised and may be subject to social censure. The instruction to talk about dying in normative terms can have the (unintended) consequence of silencing alternative views and shutting down debate. Consequently, only certain choices can be made within a limited range of options. For health services and professionals, getting people comfortable with talking about death and dying makes it easier to discuss ACP, reduce unplanned interventions and manage resources (Pollock & Wilson, 2015). The coalition of interests between the hospice movement, the death positivity movement and healthcare policy has placed an increasing focus on the healthcare aspects of death and dying, largely over-riding the social, personal, emotional, and religious elements of the experience. However, evidence from this study shows that the professional healthcare agenda is not well aligned with public perceptions and actions.

### ***Strengths and limitations***

Most previous research has been cross-sectional, utilising surveys and quantitative methods to assess public attitudes, providing little opportunity for exploration of such complex issues (Cox et al., 2013). The deliberative discussion group method had the considerable advantage of allowing participants the opportunity to reflect on, and process, their own and other peoples' views, particularly as participating in the research study provided a rare opportunity to think intently about death and dying and share these views (Seymour et al., 2009).

People took part in the study because the topic of death and dying was of interest to them and they were willing to talk about it. We recognise that respondents were self-selected and had a pre-existing interest in the topic. Some were members of special interest groups and the majority were female, older and highly educated. However, these participants were articulate and reflexive and well placed to consider the complex issues raised by the study. A number of participants took part who were not so comfortable with talking about death and dying but wanted to challenge themselves to become more knowledgeable and at ease with the topic. The move to online groups during national pandemic restrictions allowed wider geographical reach and opened contact with sections of the population that would not otherwise have been able to participate, for example those usually at work or with limited mobility. However, it also made recruitment of some groups more difficult as we could not introduce the study directly through attendance at face-to-face groups and events, such as community, social and sports clubs. This made it particularly difficult to access and recruit younger people, those from different ethnic groups, and men.

As Cox et al. note the majority of studies focus on older adults, and there is limited understanding of the attitudes of those under 50 (Cox et al., 2013). Emerging evidence is starting to show that the concerns of younger people are similar to those highlighted in this and previous studies (Robinson et al., 2019). Despite 36% ( $n = 15/41$ ) of our sample being under 50, none were under the age of 30 and we suggest the views of younger people requires greater exploration in further research.

## Conclusion

The idea that the public has an aversion to talking about death and dying, and that death remains a social 'taboo' has been vigorously promoted by a diverse range of social movements and interest groups since the 1960s. Nevertheless, then as now, there is little evidence to support these claims as attitudes to death and dying have not been extensively researched. The current vitality of the 'death positivity' movement parallels the development of demographic changes in an ageing population within which dying is increasingly likely to be rather unpleasant and protracted, occurring in great old age from a combination of increasing frailty and co-morbidity, including cognitive decline and incapacity. It is, in practice, hard to deliver a 'good death' in such circumstances. The promotion of a cultural script about the desired and appropriate way to die excludes other options and effectively constrains, rather than enables, 'choice'. It is effectively a modern form of 'death denial' and, arguably, constitutes a disservice to a population that is able to recognise a rather more grim reality.

Our findings suggest that the construct of 'the good death' and related ideas have permeated public understanding and awareness but only to a limited extent. The study participants expressed the idea that 'it was good to talk' about death and dying, without having a clear explanation of why this was. They drew on a wide range of personal and vicarious experience in sharing their ideas, acknowledging the intrinsic uncertainty and complexity of death, and the constraints this placed on future planning. Participants were realistic about the sadness and unpleasantness that can be involved in dying. Our data indicate that people have complex and nuanced ideas about the appropriateness and value of talking about death and dying, retaining a focus on individualism and diversity alongside a concern to behave considerately towards others.

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## ORCID

Eleanor Wilson  <http://orcid.org/0000-0003-0419-5901>

Glenys Caswell  <http://orcid.org/0000-0002-8246-8189>

Nicola Turner  <http://orcid.org/0000-0002-0870-8324>

Kristian Pollock  <http://orcid.org/0000-0002-6836-8595>

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