Final approval of manuscript: All authors.



"I want to die in my sleep"—how people think about death, choice, and control: findings from a Massive Open Online Course

Christine Sanderson^{1,2}, Lauren Miller-Lewis³, Deb Rawlings³, Deborah Parker¹, Jennifer Tieman³

¹Faculty of Health, University of Technology Sydney, Ultimo, NSW, Australia; ²Palliative Medicine, Calvary Health Care Kogarah, Kogarah, NSW, Australia; ³Palliative and Supportive Services, College of Nursing and Health Sciences, Flinders University, Adelaide, SA, Australia *Contributions*: (I) Conception and design: All authors; (II) Administrative support: None; (III) Provision of study materials or patients: L Miller-Lewis; (IV) Collection and assembly of data: L Miller-Lewis; (V) Data analysis and interpretation: C Sanderson; (VI) Manuscript writing: All authors; (VII)

Correspondence to: Christine Sanderson, BA, BMBS, MPH, FRACP. Faculty of Health, University of Technology Sydney, Level 3, 235 Jones St, Ultimo, NSW 2007, Australia; Palliative Medicine, Calvary Health Care Kogarah, 91-111 Rocky Point Rd, Kogarah, NSW 2217 Australia. Email: christinersanderson@gmail.com.

Background: Complex social and ethical debates about voluntary assisted dying (euthanasia), palliative care, and advance care planning are presently being worked through in many developed countries, and the policy implications of these discussions for palliative care are potentially very significant. However, community attitudes to death and dying are complex, multilayered, and contain many mixed messages.

Methods: Participants posted comments in a Massive Open Online Course (MOOC) on death and dying, entitled Dying2Learn. This provided an opportunity to explore societal and personal attitudes to wishes and beliefs around death and dying. For one activity in the MOOC, participants responded to a question asking them about "the best way to go".

Results: Responses were subjected to thematic analysis, during which they were coded for conceptual categories. This analysis showed how acceptance of death as a natural and normal process, and as a shared event that affects a whole social network, may nonetheless be accompanied by deep reluctance to address the physical process of dying (i.e., "avoidant acceptance").

Conclusions: Our findings highlighted a desire for choice and control in relation to dying, which is a common element in discussions of both advance care planning and palliative care. This same focus may contribute to a perception that voluntary assisted dying/euthanasia is a necessary strategy for ensuring that people have control over their dying process. We discuss the paradox of individuals wanting to have control whilst preferring not to know that they are dying.

Keywords: Advance care planning; attitudes to death; palliative care; qualitative research

Submitted Oct 25, 2018. Accepted for publication Mar 17, 2019. doi: 10.21037/apm.2019.03.07

View this article at: http://dx.doi.org/10.21037/apm.2019.03.07

Introduction

Whilst mortality is not yet optional, improvements in clinical care in developed countries keep pushing back the boundaries of when and how people die, challenging us as individuals and as societies. Public policy debates are occurring in many Western countries around issues related to end of life care, advance care planning, palliative care, determinations regarding futile treatment, and voluntary

assisted dying/euthanasia. These discussions have at times led to an intense public focus on issues of death and dying, and profound policy changes are likely to flow from these debates (1-5).

It is often suggested that individual decision-making about death and dying, as well as institutional and social processes of care, are driven by death-denying social attitudes (1,6,7). Phenomena such as the medicalization

and institutionalization of death (6), the reluctance of many people to participate in advance care planning conversations (8,9), or the common use of euphemisms when talking about death and dying (10), have all been taken as proxy indicators of the extent of the problem of death denial. Concerns about societal and individual death denial have led to a social movement that aims to promote community conversations about death and increase "death awareness", encouraging people to plan for their own future death, and to build capacity for more community support for dying people. Its aim is to bring death back into the public domain, making it "everyone's business" (11-14). At the most personal level, this social movement starts from the assumption that acceptance of death will mean that individuals are more likely to achieve a "good death" (15).

Yet a closer analysis of the discourse surrounding death and dving presents a very complex picture, and the hesitancy of some people to address and discuss death and dying in some social contexts can be contrasted with the intensity of the advocacy and debate that boils over in others, for example on legalization of assisted dying, or with regard to public debate in the UK about the Liverpool Care Pathway (16-19). In his survey of Kastenbaum's theory of the "death system" as applied to the USA, Corr concluded that rather than being simply death-denying, American attitudes demonstrate that denial and acceptance of death coexist (20), whilst a systematic review from the UK shows how attitudes vary greatly by age and health circumstances (21). Theoretical rebukes to simplistic conceptualizations of the "deathdenying society" are not new (22,23). Critics have suggested that rather than being death-denying, attitudes to death have simply changed as individual and societal experiences of death have changed, including through medical prolongation of life, organizational arrangement of death and dying, and the decline of religious practices associated with dying (24). It is therefore important to understand the contradictions and inconsistencies in community attitudes to death and dying, as policies and programs founded largely on the assumption that we are a death-denying society, for example those promoting advance care planning for the end of life, may falter as a result of not taking this complexity adequately into account (25,26).

This was the social and political environment in which we ran a public MOOC (Massive Open Online Course) called Dying2Learn (27). The 5-week MOOC acted as a social intervention, with the aim of fostering community conversations and strengthening community awareness of death as a normal process, as well as providing us with an opportunity to learn about contemporary Australian

attitudes to death and dying. The MOOC used a non-didactic, c-MOOC constructivist approach (28), and participants engaged online with each other and with the course facilitators. We provided course materials that were selected to trigger reflection and discussion, and activities related to personal understandings of death and dying. This approach was highly regarded by participants, many of whom reported in their comments and course reflections that the experience of participating in the MOOC was transformative (27). Uniquely, the MOOC has provided us with deep qualitative data on the death attitudes of a group of participants who were presumably mostly not facing personal illness or death at that point in their lives.

Methods

The Dying2Learn MOOC (https://www.caresearch.com. au/caresearch/tabid/2868/Default.aspx) was developed by CareSearch, the Australian palliative care knowledge network. Recruitment of participants occurred via comprehensive online promotion in social media networks, initiated through four CareSearch mailing lists and involved community partner organizations (such as The Groundswell Project https://www.thegroundswellproject.com/), who disseminated information about the MOOC. Mainstream media (radio, online news) were also used for promotion. Demand for the MOOC continued to grow from the first Dying2Learn MOOC, which was run in 2016. Ethics approval to undertake research on the MOOC was received from the Flinders University Social and Behavioural Research Ethics Committee (Project 7247) for a project entitled "Effect of supportive engagement through MOOC participation on death awareness and death attitudes".

There were 1,156 people enrolled in the first MOOC in 2016, and of these 895 went on to actively participate in activities online. The majority of participants were Australian and female, and two thirds identified themselves as health professionals. The MOOC began with one introductory week, followed by four topic weeks. The first two topics of the MOOC allowed participants to explore cultural representations of death and dying, to consider the ways it is and is not spoken about, and to investigate social practices around death and bereavement. In the third topic of the MOOC, issues related to medical experiences of death and dying were explored, and the fourth topic considered death and dying from the perspective of online experiences. The MOOC comprised, in total, 24 optional learning activities tailored to each of the topics offered (29).

The activity of interest in this study was part of topic 3, titled 'if death is the problem, is medicine the answer?'

One of the optional MOOC activities in this third topic invited participants to consider their own death and write about their views on "the best way to go." The question was worded: "Many of us have secret thoughts about what might be 'the best way to go'. Do you have any preferences? If you feel like sharing, for this activity we would like you to share what your preferences are, and why. What is the main emotion or concern that drives your preference?"

A total of 303 participants provided a response to this open-ended question, and it is their free-text responses to this activity that form the basis of the present study. Of the 303 people who participated in the specific activity reported here, 94.7% were female, 61.5% of the respondents were aged 50 and over, and 93.4% were located in Australia. Those not located in Australia were almost all from other English-speaking countries, predominantly New Zealand and the UK. Two thirds of respondents (66.9%) identified themselves as health professionals, and 71.9% had a university qualification.

Data was transferred from the online discussions by LML and uploaded into HyperResearch v 3.5.1 for thematic analysis (30). Thematic analysis can be defined as 'identifying and describing both implicit and explicit ideas' (31). The data was read by all authors and coded by CS. Coding involved close reading of the comments, generating codes to identify and make explicit the different categories of response that were evident in the data. Categories were then grouped together into major themes using the code mapping tool within HyperResearch. The code map allows identification of emergent groups of related codes which are brought together as a theme. In the final stage of the coding process participants' individual responses, which have been collected together within each theme, were reviewed yet again to explore different aspects of the meaning of that theme for participants. Analysis involved the team agreeing on the description of each theme, and then looking for divergent views within the data on each theme in order to explore the boundaries of the phenomenon, and also to characterise the full range of perspectives held by participants. All authors reviewed and agreed on the thematic analysis.

Results

Four dominant themes were identified through immersion and thematic analysis of the data and they are described below.

Dying in my sleep

A very frequent response to the question about "the best way to go" was that the preferred way to die is "in my sleep."

"I would like to go peacefully in my sleep without any suffering as I feel that this would be easier for my loved ones instead of watching me suffer."

"I would like to die of acute cardiac event in my sleep."

Apart from responses that expressed concerns about pain and pain management, this group of responses was overwhelmingly the most common wish expressed by participants. For these writers it was evident that the ideal death is one that takes a person unawares, and this was conveyed in the closely related choices of "quick" or "sudden".

"I would like to go really quick... midstride... so that everyone will clearly remember me for who I was."

"The best way to go is quickly."

"The best and only way to go is to go to sleep one night and not wake up—no pain, no worries no medical intervention and no one trying to coerce you into dying their way. Unfortunately dying quietly in your own bed is enjoyed by only a few lucky people."

For some, death during sleep was how they imagined the final stage of dying from an illness, but they still wished to have opportunities to say goodbye, and to die with companionship in their chosen environment.

"I would like to go peacefully in my sleep, have my loved ones around listening to my fave (sic) music."

This response was sometimes qualified by a recognition that their wish was just that. Some identified tensions inherent in this wish: that dying unexpectedly reduces the likelihood of being able to say goodbye to loved ones, or might mean leaving other aspects of life uncompleted.

"I often think that I would like to die quickly. Be it, something acute like a cardiac arrest, or an aneurysm. But part of me would like the opportunity to say goodbye to loved ones."

Another concern was whether for their family, or the person finding their body, a sudden death would be more traumatic than an expected death.

"I am not sure at this stage and I suppose I haven't got a choice and I keep on changing my mind as I get older, for my family's sake I would rather have a slow death so that they can get used to the thought of my departure and we still have time together, a sudden death might be nice for me but horrible for them and after all I would like to say bye-bye as well."

In a related theme, participants also stated that they hoped to die at an old age, having experienced the rewards of a full life, but avoiding the anticipated degradations of ageing.

"Sure I have a preference, but I think it's a little bit of a fairy tale ending. Just to die in my sleep at a lovely old age, pain free."

An additional concern for some participants living alone, poignantly, was fear about how long it might take for them to be found if they died suddenly.

"I do have concerns about dying alone, not that it is such a bad thing, but how long will it take someone to find me? I live alone, and I don't mind dying alone, I just wonder who will miss me enough to contact my landlady to check on me. If my brother is still alive, he would probably be concerned if he didn't hear from me for 2 or more days. We E-mail each other every day. I have another friend that I E-mail every day that might get concerned if they didn't hear from me."

Social death: the shared intimacy of dying

Many respondents approached the question from the perspective that death is an intimate, shared experience that would affect their whole social network. For them, when talking about how they would want to die, a positive communal experience was described. These people provided detailed descriptions of their wishes for family, pets, and others to be present. Often the focus was more on the needs of family and friends than on those of the dying person:

"I think that if I was aware that I was going to die very soon I would prefer to go in my sleep following a day spent with family and friends to celebrate our life together. I would like to have prepared books or letters for my children to help them through the tough times and have had the opportunity to tell them how much I love them and encourage them to live their lives to the fullest. I would like a small funeral with those close to me and I would like them to cry or laugh about situations we had found ourselves in over the years."

However, others expressed fears about being a burden or causing distress to family members. Strikingly, many participants' fear of prolonged dying seemed to be linked to concern about causing their family suffering, rather than concern about prolongation of their own suffering as the dying person.

"I'd like to die of a sudden fatal heart attack, preferably at home. This would cause least inconvenience to everybody. Although it would be a shock, particularly to the person finding the body, I think most people would find it to be less agony than waiting for an uncertain length of time as a disease progressed. For me the death would be relatively painless, and anything left undone I would have to entrust to others."

Some explicitly acknowledged the need to find a balance between a dying person's needs for support and companionship, versus the risk of overwhelming their family and supporters with distressing experiences or burdensome care.

"I would like to die at home surrounded by my family, but of course there may be many variables when the time comes, and I don't want to add any further burden to my family, so I will allow them to make that call."

With regard to death in old age, fears about how death occurs for older people concerned some participants, particularly those working in aged care, or some of those who had witnessed deaths of older friends or relatives at close hand.

"I care for the aged and find this a privilege but time and time again our elders tell us that they would rather be dead they have lived too long, what good are they to anyone. It is hard to reassure them that they still have value in their lives when they can't see it. I might be selfish but I don't want to feel that way."

"On my terms— whatever the circumstances may be I hope I am able to die my way. Not the way others think it should be. Honestly I prefer not knowing or seeing it coming. Either in my sleep, peaceful and unaware or so sudden I don't register it happening. I have a slight fear of dying, or more accurately the unknowns of dying. How it'll feel and what happens once you die. Not only that but after working in Aged Care for seven years and seeing how my residents pass away, the waiting to die and the pain would be horrible."

Physical death

The most frequent concern in the physical domain related to pain. However participants generally had high expectations regarding pain control.

"I have a fear of suffering at the end of life/I need someone overseeing my care who is prepared to provide medication that is going to maintain my comfort and allow me to have a comfortable dignified death."

A reason participants often gave for wishing to die in their sleep was concern about being aware during the dying process. Nonetheless, many still expressed the wish to know when death is approaching in order to be able to prepare, but did not want to experience dying. Although many participants said they hoped to avoid medical intervention in their dying, hardly any wanted their death to be natural to the extent of being fully aware whilst dying. The following example was very much a minority view:

"My husband and I were discussing dying the other day. He

said he would like to die quickly without realising he was dying but I would like time to prepare myself. When I think of dying I would like time to reflect on my life, not that it is exceptional in many ways but just to look quietly at many things and approach death with serenity. At one stage I had thought to have a death while in sleep but then I think to have the eye's wide open to be able to see the final journey of life."

The far more commonly expressed wish was for sleep to simply become death, whether naturally or as a result of drugs. Comments about the importance of drugs for dying patients often slid from pain management towards assisted dying/euthanasia, without clearly distinguishing the two.

"Put me to sleep with no pain."

Choice and control of dying

The imperative to be in control and the recognition that death is inherently uncontrollable often appeared side by side in participants' responses, like an unanswered koan.

"One of the main things I think that comes through from our conversations and thoughts about actually dying, is the CONTROL factor... we simply DON'T KNOW how, when death will come and we have no instructions about what WE as people are supposed to do when it comes! Throughout LIFE we have commands, rules, we learn by watching, listening, reading or by something happening to us ONCE so that if it happens again we know what to do... it's probably the ONE thing on a personal level we just can't CONTROL—like you can't say—Right. Breath deeply now... hold it... hold it longer... stop breathing NOW. Done. Nup. No text book or instructions or control panel for this one!"

"In an ideal world, I think the best way to go would be fully prepared, with everyone aware of my wishes no matter what bappened, and go quickly, no lingering or suffering. I realise this is bit unrealistic, as there are so many factors involved, Advance Care Directive and other careful planning notwithstanding."

"I don't believe we have a choice. When your time is up, it's lights out... My biggest fear is not surprisingly pain and suffering... Of course, like many people, I'd like to go to sleep and not wake up... If I linger, I would want to be pain free and with my loved ones at my side... If I had a terminal illness, or in unmanageable pain, I would want the choice to be able to hasten my death... I am an advocate for euthanasia under certain circumstances and certain conditions, it should be MY choice..."

"I would like an opportunity to farewell friends and family.

Having shared my preferences, I recognise that I could die anywhere at any time. I want to remain open to the unknown and unknowable."

The concern for control related to different aspects of

the dying process. For some, the concern was with the "aesthetics" of their death, and they wanted to control how people would perceive them and perceive their dying, and thus how they believed they would be remembered.

"I have a friend who watched her partner die and said it was awful. I think about what is the last memory of me I would want."

"It is always preferential to die in peace without pain. Unfortunately this is not always what actually happens. In the event of being bed bound, drugged up and unable to lead a quality life, please let me go surrounded by my family. If I am in pain or a picture of death, let me go behind closed doors where people can remember me as I was."

Another element of control involved detailed planning for the setting in which death would occur, in a striking analogy to "birth plans"—often including consideration of music, setting, and who should be present.

"My preference... would be to die a peaceful death with my family around me at home. Hopefully by the time I have reached this stage the scene would be set, my clothes ready. (Please don't send me off in my nightwear) my hair looking good (You know I have a thing about my hair been just right). My 3 cats ashes ready to come too (in boxes on my dressing table). My Rosary beads in my hands and hopefully some small tokens of the family affection for me. Funeral service all planned so stress on the family."

The next aspect of choice and control that we identified related to having control over medical interventions, and being able to access whatever care would be needed to be comfortable and to avoid unnecessarily traumatic treatment. Here the language of choice and control was strongly aligned with that of advance care planning. Some participants specifically identified advance care planning strategies (writing advance directives, identifying substitute decision-makers, and talking to family and friends about their preferences) as strategies to ensure their wishes would be followed.

"No suffering

No heroics

Unless I can come back as ME, independent, cognitively aware, continent and fully functioning, then let me off thanks!

And yes, my daughter is aware of my wants. Her I trust."

The final aspect of control related to the timing of death, and many participants explicitly expressed expectations about voluntary assisted death or euthanasia. The prospect of being able to access some form of assisted death seemed for many to present a simple resolution of all of their concerns about control of the dying process. What is more, it seemed consistent with the wish to "die in my sleep" or

have a quick death.

"If I had a terminal illness, I would like to be able to replicate 'the slipping away' by assisted dying/euthanasia at a place and time of my choosing."

In the quest for control over the dying process, access to drugs was regarded as significant. Drugs allow control of pain and other symptoms; there was also an expectation that drugs are used to reduce awareness of the dying process and alleviate fear and anxiety. Finally, drugs were also perceived as agents that may be used to hasten death.

"Seriously, I don't want to know what's happening. Give me every drug known that can put me in that happy place I have seen others reach and wake up dead."

Those participants who work in health care often expressed this explicitly.

"If I am 'terminal' dying from cancer, palliative terminal sedation is my choice, after saying 'Goodbye' to loved ones, just give me midazolam and morphine till I'm asleep and then unconscious, and keep it going until I naturally die. Syringe drivers are good, but may need higher doses if dying process taking too long."

A number of participants indicated that they have, or expect that they will have, a detailed plan for ensuring death on their own terms. They echoed the theme of control and choice, some of them extending the concept of palliation to explicitly include assisted dying.

"My preference... is to seek out euthanasia on my 85th birthday."

"I am very concerned about my state of mind when I am at death's door and am scared to think I may become a vegetable being kept alive because it is still illegal to die with dignity. If I am able to, I will try and put systems in place to stop this from happening."

"This exercise was cathartic. If only... but I do hope that palliation has moved ahead in leaps and bounds by the time I depart this existence in order for me to utilise my preferences. Some I think will be achievable others are still to this day, beyond my reach. My higgest fear is lack of choice and freedom to do what I would like."

Discussion

Participants could be seen dealing with the complexity about choice, planning, reality, and control when considering their "best way to go", in contrast to what they understood to be the fundamental problem of choicelessness confronting people who are dying naturally. Their words underscored the unknowability of the dying process, and the difficulty

of planning or preparing for the actual experience of death. At the same time, they frequently indicated a strong commitment to the dominant social discourse of choice and control. In order to resolve this contradiction many participants explicitly identified voluntary assisted dying as their preferred way through the dying process. For them, the expectations of dying quickly, of being able to "just go to sleep", and the need for choice and control, are all seen as being met by voluntary assisted dying. Furthermore, acceptance of voluntary assisted dying is seen as acceptance of death, which in this particular, self-selected group was a highly valued state. Thus, since choice and control are very significant concerns at the end of life for many of these participants, and along with their acceptance of dying as normal but inherently uncontrollable, it seems that for many of them the only way choice and control can in fact be guaranteed is by voluntary assisted dying/euthanasia. At the time the MOOC was conducted in 2016, voluntary assisted dying was a prevalent topic in the Australian media, but had not been legislated in any State or region. One Australian State out of eight has recently legislated to allow voluntary assisted dying, although at the time of writing the legislation had not yet come into force. The highly-debated nature of assisted dying in Australia at the time may have culturally influenced the way the topic was treated by participants.

From the perspective of health policy, many people will have the opportunity to know they are dying and to plan ahead and make choices. Advance care planning is promoted for this situation as a strategy to reduce futile and traumatic care at the end of life. Yet these highly motivated participants in a MOOC demonstrate some of the fundamental difficulties in making reality-based advance care plans. A documentary preceded the activity which reflected on the medical decisions that are made when people are close to death. This is likely to have pre-empted, to some degree, responses that focused on future planning. Nonetheless, wanting to die in one's sleep is not much of a plan. Despite a willingness to be aware of the approach of death and to face it when it is happening, the necessity to do so is still troubling for many. Rather than being deathdenying, the often-repeated wish of participants to "die in my sleep" strongly suggests what might be called "avoidant acceptance" of death and the associated experiences, where physical deterioration, symptoms, or becoming dependent on others are more feared than death itself. Furthermore, it highlights the fact that preparing for social death (dealing with one's belongings, relationships, and responsibilities) may be a much more manageable task than planning for

physical death, the experience of which can never be known in advance, but which is the focus of most end of life care policy and care provision (32).

Our results point to a significant slippage in participants' perceptions, a slide from palliative care towards assisted dying/euthanasia, via the perception that medications used for dying patients are given with the intent of eliminating both symptoms and awareness, allowing for the avoidance of unwanted or feared aspects of the dying process. We suggest that as much as palliative care and advance care planning emphasize choice and control (33,34), it is possible they may, somewhat paradoxically, be contributing to increasing social expectations about voluntary assisted dying/euthanasia in the community. Even within this very knowledgeable group, and despite the efforts of many palliative care clinicians to promote a contrary position (35), participants' statements frequently associate the provision of palliative care closely with euthanasia/assisted death. These are extremely significant considerations for palliative care practitioners to acknowledge and explore further.

Limitations

The participants in the MOOC were a self-selected population of highly motivated people who mostly resided in Australia, with a high proportion of women and people who identified themselves as health professionals. As a result they are by no means representative of the Australian community, and the findings may not be broadly generalizable. However, when we take into account the fact that these participants have a pre-existing level of death literacy that is above average, the issues identified here are more rather than less interesting. If these participants are regarded as being at one end of a spectrum of death awareness, it suggests that research to understand the values, beliefs, and perceptions of those on other parts of the spectrum is also likely to be extremely valuable, and might yield unexpected results.

Women greatly predominated amongst the participants in the MOOC. In part this reflects the reach of CareSearch within the Australian aged care sector, and suggests a significant unmet need for those working in this area, who are largely female, to reflect on the end of life issues they are exposed to in their workplaces. The extent to which the concerns raised here are specifically gendered in nature cannot be answered without further research.

Whilst health care workers made up the majority of participants, it is important to note that the MOOC was

designed to promote personal reflexivity, and many of the participants acknowledged this as the reason it was such a valuable experience. Thus their participation was framed around their own personal and existential concerns, despite—or indeed because of—their exposure to death and dying in their workplaces. The constructivist framing of the MOOC also meant that all contributions, whether from professionals or non-professionals, were valued equally, and the interactions and exchanges of knowledge between people with different standpoints itself enriched the MOOC process, and allowed people to safely challenge and explore various perspectives.

It is unclear what type of influence the web-based context of the activity may have had on the way participants chose to respond to the question posed. It is possible that the shared nature of the online responses within the socially-connected MOOC platform may have altered the way people responded, and they may have responded differently if responses were gathered in a face-to-face interview. The advantages and disadvantages of web-based versus face-to-face methodologies in relation to social desirability confidentiality, and anonymity are unknown, but the use of a web-based platform did mean that it was possible to gather responses from a broader and larger audience than would have been possible if conducted face-to-face.

Finally, the data gathered and reported in this study is based on the open-ended response to one specific question that formed one activity in a MOOC, rather than being derived from a psychometric instrument with multiple questions. The MOOC activity was part of a sequence of activities throughout the course, in which the context for the discussion was built up over a number of weeks. The qualitative analysis of the free-text responses to this activity will inform our future efforts to develop an assessment instrument relevant to the topic. Furthermore, the responses to this and other activities in the MOOC is informing future research, in which we are delving deeper in to the emotional aspects of dealing with death, and in particular, the emotionally-laden words that people use to describe how they feel about death.

Conclusions

Understanding the complexities underlying community attitudes to death and dying is essential at a time when these topics are being fundamentally re-examined in our society. Our study offers valuable, and particular, perspectives on a specific subset of the community's views on death and dying,

including as they relate to palliative care, voluntary assisted dying/euthanasia, and advance care planning. These come from a motivated and interested group of participants, who are informed and engaged. Further exploration is needed to help us illuminate the broader undercurrents within these challenging public debates, how other community groups perceive these issues, and to promote care processes that meaningfully address people's deepest concerns about how they will die. Understanding the gaps, paradoxes, and silences in this conversation is necessary if we hope to have reality-based discussion of contentious issues about death and dying in our community.

Acknowledgments

This work was supported by CareSearch, which is funded by the Australian Government Department of Health. We would like to thank the many people who contributed their time and expertise to the project, including members of the National Advisory Group and the Knowledge Network Management Group. We would also like to thank OpenLearning and The Groundswell Project for their contributions. We would also like to thank Madelaine de Valle for her administrative assistance.

Footnote

Conflicts of Interest: J Tieman, D Rawlings and L Miller-Lewis are employed by the CareSearch Project, which receives grant funding from the Australian Government Department of Health. C Sanderson has been previously employed by the CareSearch Project. The funding sponsors had no role in the design of the study; in the collection, analysis, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results. D Parker has no conflicts of interest to declare.

Ethical Statement: Ethics approval to undertake research on the MOOC was received from the Flinders University Social and Behavioural Research Ethics Committee (Project 7247) for a project entitled "Effect of supportive engagement through MOOC participation on death awareness and death attitudes". All participants gave informed content.

References

1. Swerrisen H, Duckett S. Dying Well. Melbourne: Grattan

- Institute; 2014. Report No. 2014-10. [cited 2018 Jan 30]. Available online: http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf
- Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney (NSW): ACSQHC (Australia); 2015 May [cited 2018 Jan 30]. Available online: https://www.safetyandquality.gov.au/ wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-endof-life-care.pdf
- 3. Cardona-Morrell M, Kim J, Turner R, et al. Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem. Int J Qual Health Care 2016;28:456-69.
- 4. Amsterdam S. A few questions before you go. The Monthly (Print Ed) 2017:46-7.
- Annas GJ, Galea S. Dying Healthy: Public Health Priorities for Fixed Population Life Expectancies. Ann Intern Med 2018;169:568-9.
- 6. Kellehear A. A social history of dying. Cambridge University Press, Cambridge, 2007.
- Fonseca LM, Testoni I. The Emergence of Thanatology and Current Practice in Death Education. Omega (Westport) 2011-2012;64:157-69.
- 8. Bradley SL, Woodman RJ, Tieman JJ, et al. Use of advance directives by South Australians: results from the Health Omnibus Survey Spring 2012. Med J Aust 2014; 201:467-9.
- 9. Boyd K, Murray SA. Why is talking about dying such a challenge? BMJ 2014;348:g3699.
- Rawlings D, Tieman JJ, Sanderson C, et al. Never say die: death euphemisms, misunderstandings and their implications for practice. Int J Palliat Nurs 2017;23:324-30.
- 11. Noonan K, Horsfall D, Leonard R, et al. Developing death literacy. Prog Palliat Care 2016;24:31-5.
- 12. Horsfall D, Yardley A, Leonard R, et al. End of Life at Home: Co-Creating an Ecology of Care. Penrith (NSW): Western Sydney University (Australia); 2015 May [cited 2017 Dec 1]. Available online: https://researchdirect. westernsydney.edu.au/islandora/object/uws:32200
- The GroundSwell Project. Blue Mountains Willing Villagers [Internet]. Glenbrook (NSW): The Groundswell Project. 2018 [cited 2018 Oct 8]. Available online: http:// www.thegroundswellproject.com/blue-mountains-comcom
- 14. Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. QJM 2013;106:1071-5.
- 15. Zimmermann C. Acceptance of dying: a discourse analysis

- of palliative care literature. Soc Sci Med. 2012;75:217-24.
- Seymour J, Clark D. The Liverpool Care Pathway for the Dying Patient: a critical analysis of its rise, demise and legacy in England. Wellcome Open Res 2018;3:15.
- 17. Richards N. The fight-to-die: older people and death activism. IJAL 2012;7:7-32.
- 18. McInerney F. "Requested death": A new social movement. Soc Sci Med 2000;50:137-54.
- Richards N. Assisted Suicide as a Remedy for Suffering? The End-of-Life Preferences of British "Suicide Tourists". Med Anthropol 2017; 36:348-62.
- 20. Corr CA. The death system according to Robert Kastenbaum. Omega (Westport) 2014-2015;70:13-25.
- Cox K, Bird L, Arthur A, et al. Public attitudes to death and dying in the UK: a review of published literature. BMJ Support Palliat Care 2013;3:37-45.
- 22. Walter T. Modern death: Taboo or not taboo? Sociology 1991;25:293-310.
- 23. Zimmermann C, Rodin G. The denial of death thesis: sociological critique and implications for palliative care. Palliat Med 2016;18:121-8.
- 24. Tradii L, Robert M. Do we deny death? II. Critiques of the death-denial thesis. Mortality 2017. doi: 10.1080/13576275.2017.1415319
- 25. Robins-Browne K, Palmer V, Komesaroff P. An unequivocal good? Acknowledging the complexities of advance care planning. Intern Med J 2014;44:957-60.
- 26. Billings JA, Bernacki R. Strategic targeting of advance care planning interventions: the Goldilocks phenomenon. JAMA Intern Med 2014;174:620-4.

Cite this article as: Sanderson C, Miller-Lewis L, Rawlings D, Parker D, Tieman J. "I want to die in my sleep"—how people think about death, choice, and control: findings from a Massive Open Online Course. Ann Palliat Med 2019;8(4):411-419. doi: 10.21037/apm.2019.03.07

- 27. Rawlings D, Miller-Lewis L, Collien D, et al. Lessons Learned from the Dying2Learn MOOC: Pedagogy, Platforms and Partnerships. Educ Sci 2017;7:67.
- Ebben M, Murphy JS. Unpacking MOOC scholarly discourse: a review of nascent MOOC scholarship. Learn Media Technol 2014;39:328-45.
- 29. Tieman J, Miller-Lewis L, Rawlings D, et al. The contribution of a MOOC to community discussions around death and dying. BMC Palliat Care 2018;17:31.
- 30. Nowell LS, Norris JM, White DE, et al. Thematic Analysis. Int J Qual Methods 2017;16:1-13.
- 31. Guest G, MacQueen KM, Namey EE. Applied thematic analysis. Thousand Oaks, CA: Sage, 2012.
- 32. Borgstrom E. Social death in end-of-life care policy. Contemp Soc Sci 2015;10:272-83.
- 33. The Clinical Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. 2011. A National Framework for Advance Care Directives, Canberra. Australian Government Department of Health and Ageing. Available online: https://www.dementia.org. au/files/start2talk/5.0.4.1%20AHMAC%20framework.pdf
- Bartel R. Conversations: Creating Choice in End of Life Care. Melbourne. 2016. Available online: http://achr.org. au/wp-content/uploads/2016/02/Conversations-Choicein-End-of-Life-Care-ACHR-20161.pdf
- De Lima L, Woodruff R, Pettus K, et al. International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide. J Palliat Med 2017;20:8-14.