

Will Voluntary Assisted Dying see new social rituals evolving?

Rawlings D, Winsall, M Miller-Lewis L, Tieman J.

@deb_rawlings

deborah.rawlings@flinders.edu.au

Background

- CareSearch Dying2Learn Massive Open Online Course (MOOC) held in 2016, 2017, 2018, 2020 [1]
- Week 3 of the 2018 Dying2Learn MOOC
- Qualitative data in the form of participant responses to an open-ended activity were collected.

- The activity invited participants to reflect on what would change for families and friends if **people choose to die** rather than dying 'naturally' and what, if any, rituals surrounding this act could emerge.



Ethical approval related to the Dying2Learn MOOC was granted by Flinders University Research Ethics Committee (Project 7247).

MOOC participants

- Most of the MOOC participants were female (92.5%), with a mean age of 51 years.
- Most participants resided in Australia (90.4%), although a small proportion resided in other countries including New Zealand (3.9%) and Canada (1.8%).
- Most participants reported to have completed some form of university study (67.3%) or trade school (18.1%).
- Most participants identified as a health professional (77.2%)
- When asked about their experience in caring for someone with a terminal illness, most participants reported that they were either currently or had done so in their personal lives (64.0%) and/or as a health professional (68.5%).

Data analysis

- The data were de-identified, and imported into the NVivo 12 software package, with each statement classed as an 'open-ended' response.
- In order to add rigor to and improve the reliability of the analytical approach[2] cross-verification coding was completed with coding of a randomly generated set of 51 participant statements (10% of total statements) against researcher previously defined coding schema.
- The emerging themes and subthemes were classified in to two broad overarching categories, relating back to the MOOC questions posed to participants,
 1. Views held in relation to VAD/MAID
 - 2. The rituals and funerals envisaged pre and post death (the focus of this paper)**

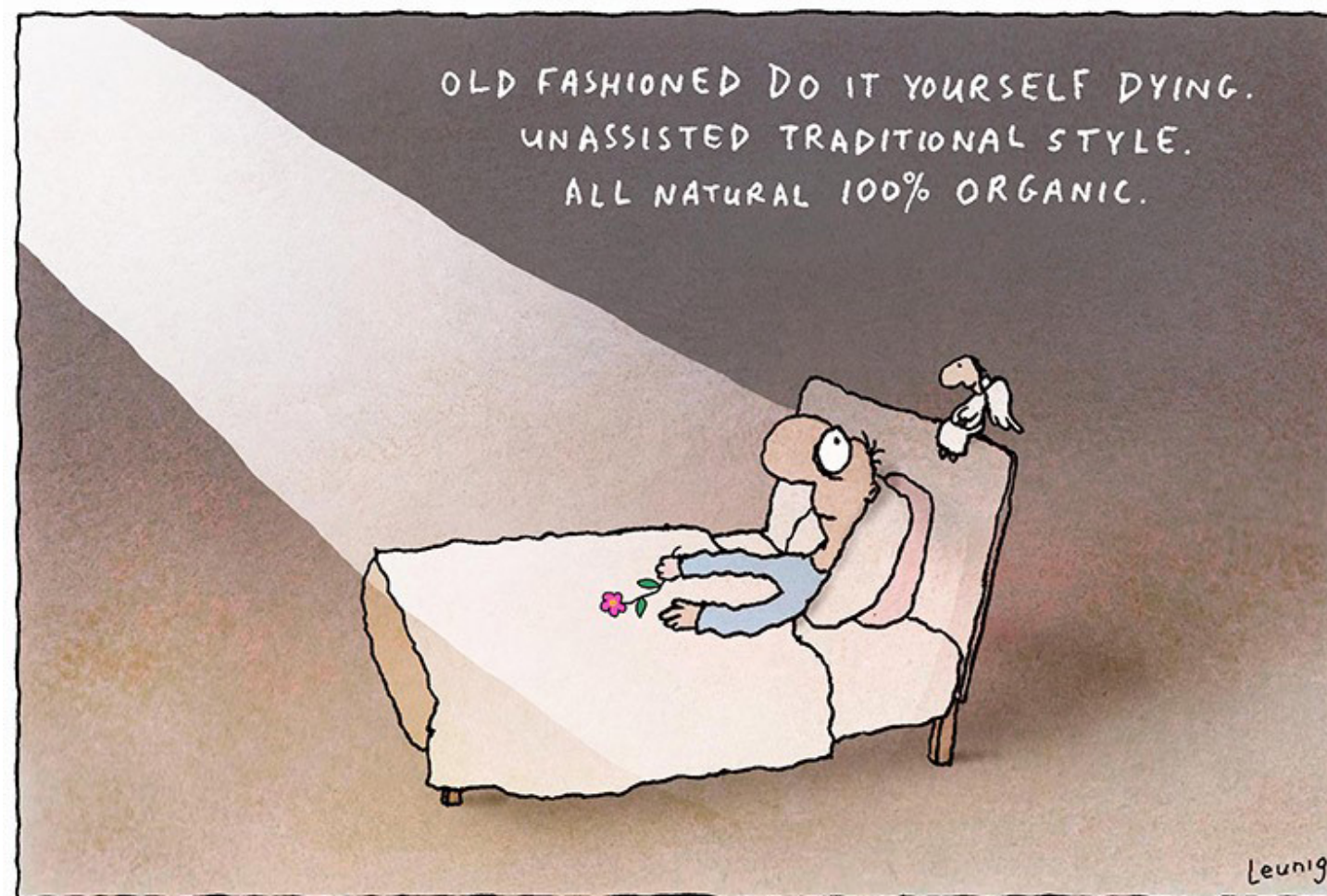
n=508 participant statements responding to the activity were extracted from the MOOC learning platform.

Conflicting thoughts of MOOC participants about VAD itself

- *“There is something about the 'mystery' of the timing of death that sits with me. That it is unknown can be a challenge to families but it can also shape a space of healing, reflection and love around the dying person. Taking control of the timing of death does not sit well with me....”*
- *“What if the process of the body gradually letting go (or abruptly, as the case may be), has some particular benefit for our soul that we can't predict? Would choosing the date of our death interfere with that? Of course, I have no idea ... “*

Dying naturally

“I suppose I have to think about what is dying naturally. These words seem to conjure up the image of lying peacefully in my own bed and dying comfortably at a ripe old age, with family and friends gathered around. They would be waiting for the last pearls of wisdom to pass from my lips on my fading breath, can't really see it happening.”



Dying 'naturally' versus choice

“While I can understand people avoiding pain and suffering, I personally believe that I do not have the right to determine my time of death”

“To be honest it seems so unnatural to me to choose the time to die.”

“It certainly would be scary to have an actual date of death, feels like way to (sic) much information. Choosing when you are going to die I think would impact on the way you live your life feels really intense. I like the idea of what will be will be”

Medical intervention?

“I may feel differently when I am at death's door but at present I wish to have control over my departure.”

“Personally I think choosing my death day and the circumstances is exactly what I want to do. I want the opportunity to prepare my daughter for losing me. I want to have a peaceful good death. I am not much for rituals and have no beliefs about what happens after I die. But I would like to be able to put the full stop on my own sentence. I believe I would be happy to die alone. I don't need a celebration or an event. When I'm done I'm done. Maybe this would change if I got a terminal diagnosis but I don't think so”

Rituals

“A ritual has been defined as a sequence of activities involving gestures, words, and objects performed in a specific place and sequence of time. Rituals encase memories and link the past with the present.” [3]

“Rituals allow expressing emotions; feeling secure in the midst of chaos; ordering experiences outside our control; reinforcing group ties; communicating thoughts, ideas, and feelings; reinforcing values; entering into a change of status; marking a rite of passage; expressing grief; articulating meaning and purpose; and transforming what is ordinary into the extraordinary, sacred, and holy” [3]

Results

Rituals before Death

This theme encompasses all comments about rituals, events or practices specifically carried out before a person dies. Five subthemes fall under this theme.

- Living wakes, parties and celebrations (n=213, 41.9%)
- Respect for individual wishes (n=94, 18.5%)
- Personal Fulfilment (n=29, 5.7%)
- Time with Loved ones (n=28, 5.5%)
- Leaving a legacy (n=12, 2.4%)

‘Living’ wakes, parties and celebrations

Comments related to celebrations, wakes, parties or funerals which are carried out before the person dies. These are sometimes referred to as a ‘living’ wake or funeral, or a ‘pre-death wake’, which the dying person attends, or could be described as a party or special gathering or celebration with friends and family to ‘celebrate life’:

“I wonder if death will go the way of high school graduations, weddings and pregnancy..... I worry that death will come with an events coordinator and a social media platform for likes. Imagine your life being rated by how good your funeral is...actually does that already happen? Imagine if the event was all planned and you changed your mind and ruined everything”

‘Living’ wakes, parties and celebrations

- *“I (sic) sure we would see an industry developed of planned death "party planners".*
- *“I think when death becomes a choice, many of those dying would do something to "celebrate" their last days”*
- *“I hate the idea of a pre death party - what if no one turns up??? I don't like a party at the best of times - how will the small talk unfold? “*

Respect for individual wishes

Comments around the importance of respecting and honouring the cultural background and traditions, preferences, choices and wishes of the dying individual and their loved ones

“Rituals are very individual and personal to the person and their families.”

“I think that rituals would be really important in the case of a known death date. How wonderful for the dying person to be in control, to have the opportunity to create ritual and hold space for themselves and their loved ones.”

Personal fulfilment

Comments around the dying individual doing things of a personal nature, e.g. achieving or participating in certain activities, creating things, visiting certain places, writing their own eulogy, or participating in symbolic or spiritual practices, before they die.

“As the dying person, I might like to release balloons into the sky, representing the spirit of my life soon to be lost.”

“I would love the opportunity to write my own eulogy...that way I'm not relying on someone else to write my story”.

“...some people are even building and painting their own casket.”

Time with loved ones

Comments around the dying individual spending quality time with family and friends, saying their goodbyes, talking, and expressing their love, before they die.

“Before I enter my end-of-life stage, while I still have my consciousness, I need to have time to say my goodbyes to family and friends so that I can be at peace with my private world. I would like my loved ones to remember me how I was before my decline.”

“People who have time to come to terms with imminent death gravitate to spending time with loved ones.”

“...telling loved ones that you love them.”

Leaving a Legacy

Comments related to the dying individual leaving things behind for others, e.g. giving away their possessions, giving gifts to people, or writing letters or notes.

“You may like an aspect of Romani tradition. In our culture things are 'bequeathed' before we die. [...] This gets rid of a lot of burden to those left behind. Also no disputes as it's all sorted, often years ago.”

“I know a lady who purchased gifts for the people that will be left behind so that they would have one last gift from her that had meaning to both of them and that they could keep for the rest of their lives.”

“Wouldn't it be wonderful if it were our community practice that, upon hearing of someone's impending death, we all wrote letters to the person, thanking them and relaying our most precise memories and learnings from contact with them.”

Conclusion

- Conflicting thoughts about VAD and choosing your own date of death
- Views on natural versus medicalised death (whatever a natural death is...)
- Parallels with other work from the D2L MOOC – bucket lists, “Before I Die”, legacy work.
- Parallels with other work on attending your own wake, ACP.

- The concept that rituals will develop around VAD in much the same way that they have around most things (weddings, christenings /naming ceremonies)
- Rituals will evolve and may help all involved to process what is happening and make lasting memories

A final word

“To die or not to die? That is not the question but instead “How to die?” We all value different things - parties for some, moments of quiet solitary reflection for others My concern with rituals prior to death is that the bereaved will be forgotten. It seems that currently our rituals after death are for honouring the deceased but also importantly (sic) for supporting the loved ones of the deceased. If we hold the honouring rituals before the death then what rituals will we hold after the death? What reason will we have for gathering? No answers but something to think about”

“Depending on how it was approached, it might make each passing minute increasingly fretful, important and desperate too. On the death day a celebration per se might be rather challenging for many. A while beforehand when death is still more theoretical for many, could make the celebration of their life easier to maintain. I would expect it would be impossible to avoid considerable mourning on the assigned death day. Separating the days would allow for a thoroughly good celebration with the person involved and a deep mourning as well when the person has died. Both these would be social rituals that would help the dying and those who care for the person dying”

References

- [1] Tieman J. et al (2018). The contribution of a MOOC to community discussions around death and dying. *BMC Palliat Care*. 2018 Feb 20;17(1):31. doi: 10.1186/s12904-018-0287-3.
- [2] Vaismoradi, M.; Turunen, H.; Bondas, T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs. Health Sci*. 2013, 15, 398–405,
- [3] Pace, J. C. and T. S. Mobley (2016). "Rituals at End-of-Life." *Nurs Clin North Am* **51**(3): 471-487.