Community Views: Analysis of ‘Before I Die’ statements

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Background
Public health movements have sought to bring death back into the open through initiatives such as death cafes, compassionate communities and arts festivals which seek to create cultural change around death and dying.

‘Before I Die’ is a participatory public art project created by Candy Chang where people could start a conversation, writing their wishes and aspirations on a public chalkboard. It has since grown into a global project with more than 4,000 ‘Before I Die’ walls presented in over 75 countries and in 36 languages (https://beforeidieproject.com/). This approach offers a modern ritual that restores perspective and invites us to consider the things which connect us. [1]

Aim
This study describes the responses made to a virtual ‘Before I Die’ within an online learning platform.

Methods
The ‘Before I Die’ activity was undertaken as part of an online massive open online course, or MOOC, called Dying2Learn conducted in 2016 and 2017. [2] In 2016, 1,156 people enrolled in the course with 219 participating in the ‘Before I Die’ activity. The 2017 MOOC saw 1,960 enrolees with 414 participating in the ‘Before I Die’ activity. The ‘Before I Die’ responses from both courses were extracted and de-identified.

Generation of an initial coding system occurred through independent coding of 50 responses by the three investigators. A trial of the coding system using a further 100 responses was undertaken and discrepancies in coding quantified and analysed. Two research assistants then independently coded the entire response set of 633 statements. Ethical approval was granted by Flinders University (SBREC 7247).

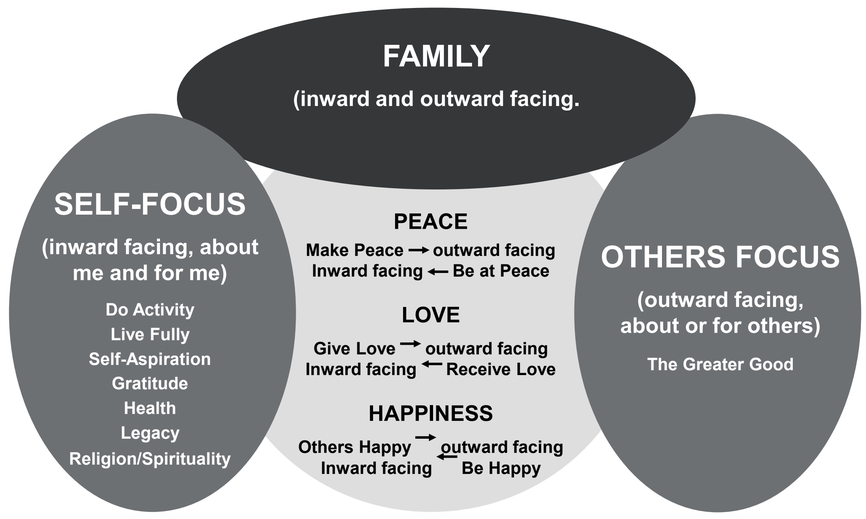


Results
Data from 633 participants who responded to the ‘Before I Die’ activity in 2016 and 2017 was collected. The respondents were predominantly female (93.3%), with a mean age of 49.75 (SD=11.91, range of 19 to 81 years, with 22.2% aged 60+). Most participants resided in Australia (87.5%), with the remainder representing 16 other countries (predominantly English-speaking). The sample were generally well educated, with 67% having completed university studies, and 73.8% identifying themselves has having a health professional occupational background.

Overall, the 633 statements by participants were assigned 1,313 codes, or an average of 2.07 codes per statement. Twelve themes emerged from the data: family; do an activity; personal aspiration/self-identity; live life fully, happiness; love; wider social impact/greater good; peace; legacy; feel appreciative/gratitude; religion/spirituality; and health. [3]

From this coding and analysis, three higher order themes emerged suggesting that wishes and aspirations related to the self (e.g., do some activity), were other focussed (e.g., make the world a better place) or encapsulated the family (e.g., doing things with the family, wanting to see grandchildren grow up). We have categorised these three higher order themes as:

1. Self – focussed /about me / inward facing
2. Others focussed / the greater good / outward facing
3. Family / about me and about others / both inward and outward facing



Discussion and Conclusions
The data shows how ‘well’ community members view what is important while considering their death.

Reflecting on what is important and on what a person wishes to achieve or address before they die can be seen as a companion process to advance care planning which addresses what an individual wants to plan to manage their actual death.

While this study is limited by a sample of convenience, it is one of the first to systematically empirically code and analyse the way that people respond to the question ‘Before I Die, I want to…’ This activity encourages people to articulate values in their life more consciously, within the context of understanding that life is finite.



References
1. Before I Die. *About Us.* 2019 [cited 2019 May 14]. Available: https://beforeidieproject.com/about
2. 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.
3. Rawlings D, Miller-Lewis L, Tieman J. Community Views on ‘What I Want Before I Die’. Behav Sci (Basel). 2018 Nov 30;8(12). pii: E111. doi: 10.3390/bs8120111.

The Dying2Learn MOOC was conducted as part of the CareSearch Project.
CareSearch is funded by the Australian Government Department of Health.

INSPIRING ACHIEVEMENT

ABN 65 542 596 200, CRICOS No. 00114A