

Community views on 'What I want before I Die'

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Dying2Learn Massive Open Online Course [1]

Before I die walls

- This approach offers a modern ritual that restores perspective and invites us to consider the things which connect us.[2]
- *At their greatest, our public spaces can nourish our well-being and help us see that we are not alone as we try to make sense of our lives". (Candy Chang) [2]*



San Francisco, USA. (image source)

Ethical approval was obtained from the Flinders University Research Ethics Committee (Project 7247).

Permission was obtained from the Before I Die Project (ongoing)
<https://beforeidieproject.com/about>

Dying2Learn Massive Open Online Course

Respondents (n=633)

Predominantly female (93.3%)

Mean age of 49.75 (range of 19 to 81 years) with 22.2% aged 60+.

Most 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
73.8% identified themselves as having a health professional occupational background

Data analysis

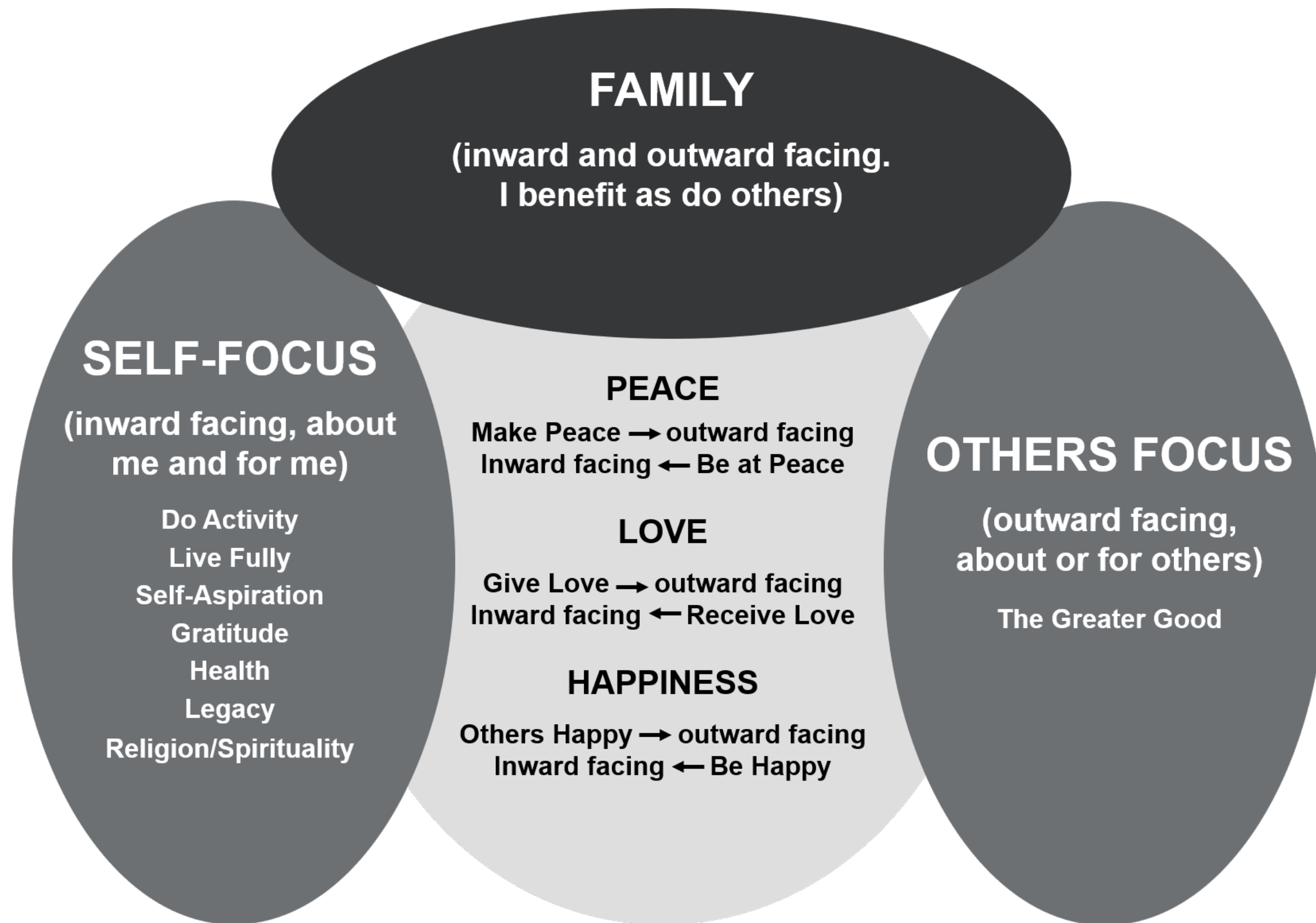
- All authors independently coded the first 50 'Before I Die' statements from both the 2016 and 2017 datasets.
- The second round of coding saw two authors compiling the coding schemes independently derived by the three authors in the first round of coding.
- These themes were refined, examined for inter-relationships between the characteristics labelled, and then combined into one set of primary coding themes.
- Further coding determined an inter-rater agreement rate of 93.33%.
- Two university psychology students independently coded all 633 responses to the 'Before I Die' activity based on the coding-guide created from coding the development cohort.
- The two independent raters obtained 95.24% agreement on all the judgements made. The Cohen's Kappa for inter-rater agreement was 0.789, $p < 0.0005$.

Theme	Definition	Example
1. Family	Family, friends and relationships with loved ones.	<i>"Before I die I would like the family re-united"</i>
2. Do an activity	The desire to personally experience a specific activity	<i>"Fly in an air balloon"</i>
3. Self-Identity	Personal goals people wished to achieve for themselves,	<i>"I want to get to know myself a whole lot better"</i>
4. Live Life Fully	A desire to have no regrets, live in the moment, and enjoy life.	<i>"Live with compassion and find meaning in every day"</i>
5. Happiness	A desire to be happy themselves or for others to be happy	<i>"See my children have happy, healthy, peaceful lives"</i>
6. Love	Love in many contexts, whether that be to receive or give love to others	<i>"I want to experience unconditional love"</i>

Themes

- 12 Themes emerged
- The top 6 themes > 100 mentions.
- Health and religion least mentioned
- Materialistic factors – barely mentioned

Theme	Definition	Example
7. The Greater Good	Wishes to impact society more widely, by making the world a better place	<i>"Make a great contribution to humanity"</i>
8. Peace	Responses mentioned peace, and included both being at peace and making peace with others	<i>"Make peace with my ex husband"</i>
9. Legacy	What they leave behind after death	<i>"Know that I mattered"</i>
10. Gratitude	Experiencing gratitude and appreciation	<i>"I want to feel truly grateful for every day"</i>
11. Religion /Spirituality	Religious or spiritual element	<i>"Feel safe and serene in the presence of God"</i>
12. Health	Health of self or family	<i>"See my children grow into healthy, happy adults"</i>



Three higher order themes which we have categorised as:

- Self-focussed/about me/inward facing (assigned 837 times)
- Others focussed/the greater good/outward facing (assigned 235 times)
- Family/about me and about others/both inward and outward facing (assigned 241 times)

(Inward and outward facing: “be loved” and “love others” “be at peace” and “make peace” “Be happy” and “others to be happy”)

#PCNA2020

Dying2learn

- Sample of convenience
- Presumed 'well' community members
- Encourages people to reflect on their values, mortality and consider what really matters
- Potential to build death awareness and preparedness
- Companion to ACP

- **FUTURE RESEARCH**
- MOOC 2018 participants completed the Before I Die activity, then completed the Valued Living Questionnaire
- Then we said: *"Now imagine that you only have 8 weeks left to live....would your answer change?"*
- Watch this space!

Thank You for Coming

[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] Before I Die. *About Us*. 2019 [cited 2019 May 14]. Available:
<https://beforeidieproject.com/about>

[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.