Dying2Learn: Cumulative Findings and Implications

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palliative care knowledge network

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We recognise that Flinders operates on Indigenous peoples' traditional lands and waters and acknowledge their continued responsibility to care for country at the University's various teaching locations, including the lands and waters of the following peoples: Kaurna, Arrernte, Boandik, Bungarla, Gunditjmara, Jawoyn, Larrakia, Nauo, Ngarrindjeri, Peramangk, Wurundjeri, Yolgnu.

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Session

To present a critical reflection on the Dying2Learn program and its contribution to palliative care.

- Overview of Dying2Learn
- The opportunity of real time conversations
- Implications and futures

Acknowledging: Deb Rawlings, Lauren Miller-Lewis, Deb Parker and Chris Sanderson. There would be no Dying2Learn without our facilitator team

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A simple idea

Dying 2 Learn

2015-2017 CareSearch work program included:

Development of a MOOC on death, dying and palliative care in Australia to build community awareness of palliative care and death as a normal process

Intent was to provide a safe space for the general public to learn about and discuss death and dying

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The Bliss of Ignorance

Why a MOOC? How a MOOC?

Growing interest in death cafés, public health approaches; Ability to connect digitally; Adult learning principles; Able to use diverse media; Readily available platforms; Free, open access

Facilitators were experienced but diverse with specific interests; Lens on death and dying - not a palliative care module; Intent to engage with public and community broadly; Trying to figure out what was a MOOC; Genuine interest in building understanding; Intent to build a constructive MOOC; Commitment to evaluation; Dealing with practicalities (licensing, copyright, permissions)

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Paradoxes around death and dying

Death is universal but framed within personal, familial, cultural and societal systems.

Death as natural conclusion to every life but also a medical event. And, given we say we want to die at home why do most of us die in hospital?

Society is changing. Increasingly digital; changing work and family patterns; geographically spread; consumer care expectations.

Population ageing, disease patterns, increase pressures on health systems, new models (eg compassionate communities, VAD, death doulas).

So, why when we are living longer with greater access to information are we still surprised by death?

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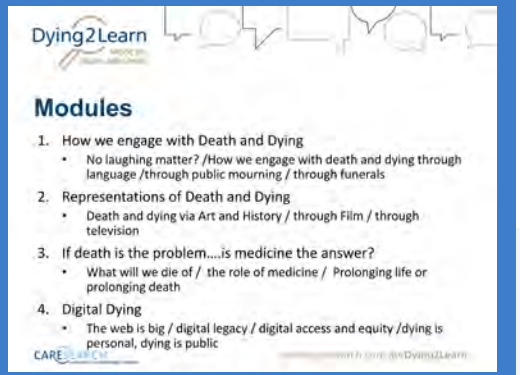
Course structure



Orientation Week

Module 1: How we engage with death and dying

Module 2: Representations of death and dying

Module 3: If death is the problem...Is medicine the answer?

Module 4: Digital Dying

The Last Post: Final Reflections

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Defining the Core Construct

Supporting people being comfortable talking about death and dying Assessed by:

- Death Comfortableness: Four statements using 5-point Likert scale
- Death Competence: Perceived knowledge and skills for coping with death, along with attitudes and beliefs about these abilities
- Coping with Death Scale: 30 item self-report questionnaire using 7-point Likert scale

Exploring the concept broadly and narrowly through course metrics, enrolment data, formal scales and qualitative analyses

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The key questions

Project Deliverable

Can we deliver a MOOC about death and dying and get 500 people to sign up?

Evaluation Aim:

Is the course valued? And are people more comfortable talking about death and dying?

Research Study:

Can we determine what effect online learning and discussions within a MOOC on death and dying have on participants' feelings and attitudes towards death and dying as measured by the Coping with Death Scale?

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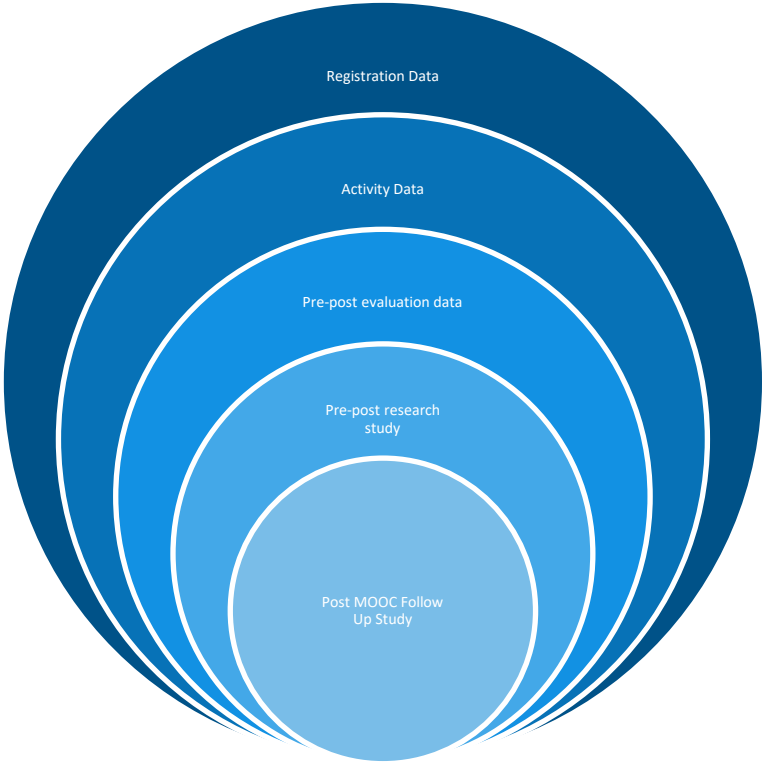

Participants advised at enrolment about registration & evaluation data
Formal ethics for the inclusion of a pre-post research study
Ethics amendments for:
-analysis of activity data
-follow up study at 6 months
-additional or replacement scales in 2017, 2018 & 2020

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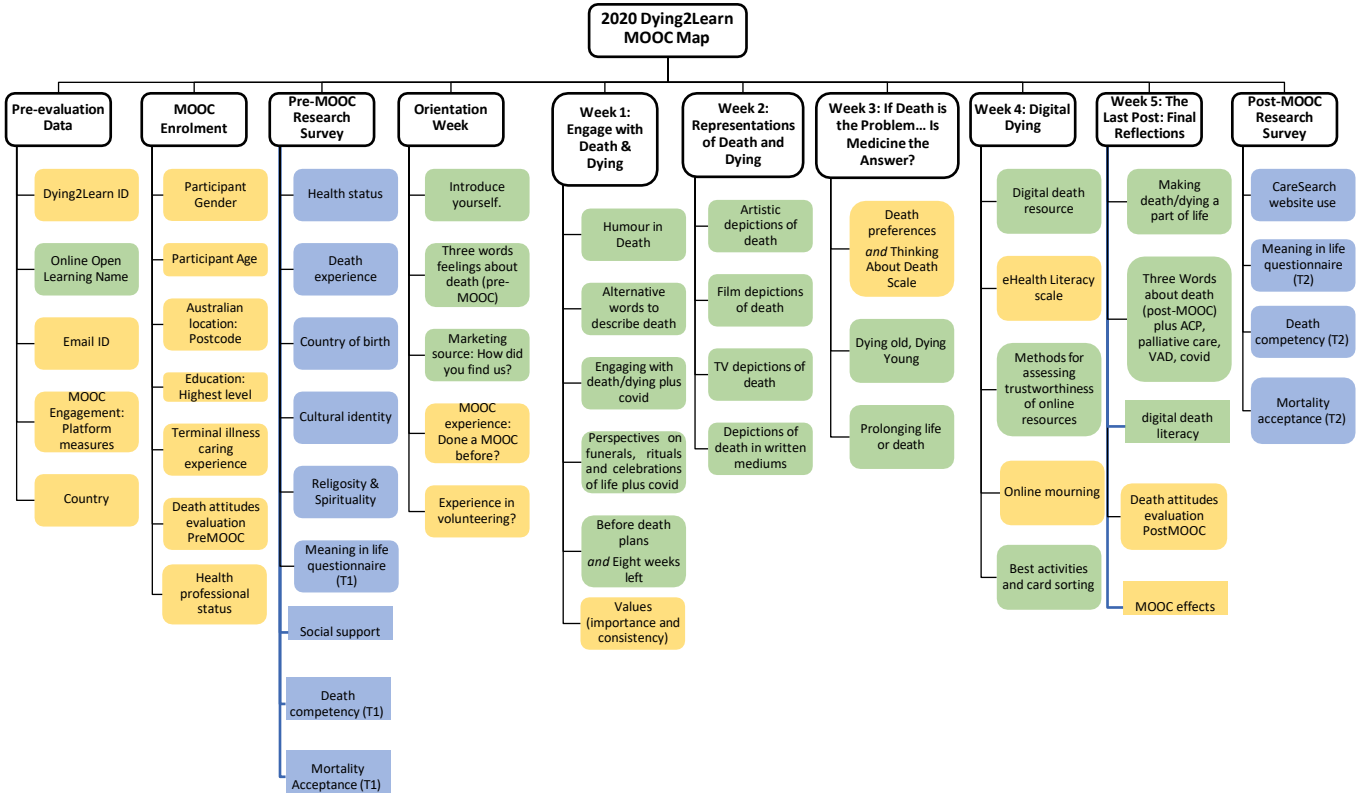
2020 Dying2Learn MOOC Map
Pre-evaluation Data
Dying2Learn ID
Online Open Learning Name
Email ID
MOOC Engagement: Platform measures
Country
MOOC Enrolment
Participant Gender
Participant Age
Australian location: Postcode
Education: Highest level
Terminal illness caring experience
Death attitudes evaluation PreMOOC
Health professional status
Pre-MOOC Research Survey
Health status
Death experience
Country of birth
Cultural identity
Religosity & Spirituality
Meaning in life questionnaire (T1)
Social support
Death competency (T1)
Mortality Acceptance (T1)
Orientation Week
Introduce yourself.
Three words feelings about death (pre-MOOC)
Marketing source: How did you find us?
MOOC experience: Done a MOOC before?
Experience in volunteering?
Week 1: Engage with Death & Dying
Humour in Death
Alternative words to describe death
Engaging with death/dying plus covid
Perspectives on funerals, rituals and celebrations of life plus covid
Before death plans and Eight weeks left
Values (importance and consistency)
Week 2: Representations of Death and Dying
Artistic depictions of death
Film depictions of death
TV depictions of death
Depictions of death in written mediums
Week 3: If Death is the Problem... Is Medicine the Answer?
Death preferences and Thinking About Death Scale
Dying old, Dying Young
Prolonging life or death
Week 4: Digital Dying
Digital death resource
eHealth Literacy scale
Methods for assessing trustworthiness of online resources
Online mourning
Best activities and card sorting
Week 5: The Last Post: Final Reflections
Making death/dying a part of life
Three Words about death (post-MOOC) plus ACP, palliative care, VAD, covid
digital death literacy
Death attitudes evaluation PostMOOC
MOOC effects
Post-MOOC Research Survey
CareSearch website use
Meaning in life questionnaire (T2)
Death competency (T2)
Mortality acceptance (T2)

Could we get people to come to our MOOC?

	2016 n=1,156		2017 n=1,960		2018 n=1,602		Cumulative n=4,718	
	n with data	M (SD) or %, range	n with data	M (SD) or %, range	n with data	M (SD) or %, range	n with data	M (SD) or %, range
Gender (female)	1156	92.6%	1949	92.3%	1590	91.8%	4695	92.2%
Age	1148	49.5 (12.3), 16-84	1956	47.2 (12.3), 17-82	1590	47.7 (12.8), 18-90	4694	47.9 (12.5), 16-90
Located in Australia	1156	93.8%	1960	73.9%	1602	88.6%	4718	83.8%
Located outside major Australian cities[b]	1078	39.1%	1469	37.5%	1438	37.5%	3985	37.9%
Self-identified health professional	1154	68.0%	1958	73.2%	1599	79.0%	4711	73.9%

Source: MOOC enrolment data 2016-2018

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What did they think of it?

MOOC engagement and post MOOC evaluation for 2016-2018 participants who commenced the MOOC.	
	M (SD), range
MOOC engagement measures (n = 3,157)	
Average percentage of course progress	49.1 (37.5), 1-100
Average number of comments made in MOOC	11.1 (18.5) 0-632
Post-MOOC Evaluation & Death Attitudes (possible range 1-5) (n = 1,036)	
MOOC was enjoyable	4.6 (0.6)
MOOC met expectations	4.5 (0.7)
Would recommend MOOC to others	4.6 (0.6)
MOOC gave deeper understanding of death	4.4 (0.7)
Gained personal insight into own beliefs	4.4 (0.8)
Feel comfortable talking to people about MOOC content	4.6 (0.6)

Source: MOOC activity data and evaluation data

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Did they feel more comfortable talking about death and dying?

	2016		2017		2018		Cumulative	
Attitude Statements	Pre-MOOC M (SD)	Post-MOOC M (SD)	Pre-MOOC M (SD)	Post-MOOC M (SD)	Pre-MOOC M (SD)	Post-MOOC M (SD)	Pre-MOOC M (SD))	Post-MOOC M (SD)
Death is a normal part of life	4.60 (0.93)	4.85 (0.40)	4.61 (0.88)	4.89 (0.32)	4.56 (0.93)	4.84 (0.45)	4.59 (0.91)	4.86 (0.39)
I am comfortable talking about death and dying	4.25 (0.94)	4.53 (0.63)	4.32 (0.88)	4.55 (0.59)	4.23 (0.91)	4.51 (0.45)	4.27 (0.90)	4.53 (0.61)

Death Attitudes were positive at commencement but increased significantly following participation.

Source: Tieman, J., Miller-Lewis, L., Rawlings, D. et al. The contribution of a MOOC to community discussions around death and dying. BMC Palliat Care 17, 31 (2018).

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Did death competence improve?

	2016		2017		2018		Cumulative	
	n with data	M (SD), range	n with data	M (SD), range	n with data	M (SD), range	n with data	M (SD), range
Pre-MOOC death competence	277	155.0 (27.4), 61.0-204.0	534	155.6 (25.2), 57.9-204.0	374	153.6 (24.9), 71.0-203.0	1185	154.8 (25.6), 57.9-204.0
Post-MOOC death competence	148	165.3 (21.9), 78.0-201.7	204	164.6 (21.5), 77.0-202.0	177	162.4 (21.1), 99.0-198.0	529	164.1 (21.5), 77.0-202.0

….. The gains in death competence made by participants in the MOOC imply that as a consequence of the course, they felt more capable of handling what is required when faced with death, and the impact was a sizeable effect of practical significance.

Miller-Lewis L, Tieman J, et al Can Exposure to Online Conversations About Death and Dying Influence Death Competence? An Exploratory Study Within an Australian Massive Open Online Course. Omega (Westport). 2020 Jun;81(2):242-271. doi: 10.1177/0030222818765813.

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Did anything change in the real world?

	% Done it	% Thinking about doing it	% Not sure if I will	% Don't intend to do it
I aim not to use euphemisms unnecessarily (n=631)	47.9%	9.8%	9.4%	23.1%
I have talked with my family or friends about what I learned in the MOOC (n=635)	78.6%	7.7%	4.7%	4.6 %
I have suggested some films/shows about death and dying to friends and family (n=637)	43.5%	21.8%	15.7 %	10.2%
I have started a conversation about death and dying at work (n=637)	66.5%	6.9 %	5.0%	3.1%
I have visited some websites providing information on death (n=638)	77.0%	10.2%	5.0%	4.1%
I have looked for information on advance care planning (n=637)	74.7%	13.5%	2.8%	3.0%
I have talked with family and friends about planning for the future (n=635)	45.4 %	38.3%	6.5%	3.5%
I have suggested to others that they sign up for the MOOC (n=638)	69.6%	18.7%	3.9%	3.4%
I have been to a death and dying event (n=633)	49.9%	18.3%	14.1%	8.4%
I have started planning my digital legacy (n=635)	22.5%	31.5%	18.9%	13.9%

Source: Follow up surveys 2016-2018. Unpublished data

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After each MOOC we all said “Never again”!

For 6 weeks, facilitators are “on duty”. You go to your day job and during lunch time you check comments, module activities. You get to sleep really late and check the MOOC before you go to work the next day!

For the 2020 MOOC, we built six modules , covering 20 topic areas with 34 activities. We developed and delivered a marketing campaign. We had to be sprightly during the course and consider 9,292 comments.

And then we needed to undertake analysis, complete reporting, and consider publications.

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Another opportunity: Real time conversations

Engaging in real time meant that courses had to evolve to deal with the social and health context in which they were being delivered.

Recognising that the world is changing quickly, and that unanticipated and foreseeable changes were in play

Unique chance to explore attitudes and feeling arising from VAD and Covid

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Case Study 1: VAD

An activity was developed, which saw participants invited 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.

1. **The rituals and funerals envisaged pre and post death.**
2. **Views held in relation to VAD / MAiD**

Participant statements (n=508) responding to the activity were extracted from the MOOC learning platform and analysed

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Rituals and funerals envisaged relative to VAD

- Living wakes, parties, and celebrations (n=227, 44.7%)
- Respect for individual wishes (n=120, 23.6%)
- Time with loved ones (n=46, 9.1%)
- Personal fulfilment (n=34, 6.7%)
- Leaving a legacy (n=16, 3.1%)
- General views on rituals before death (n=19, 3.7%)

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Real time voices around VAD

While asking about rituals and funerals we realised that many participants were taking the opportunity to comment generally about VAD

This cohort within the MOOC, despite consisting of many health professionals and of those with a higher level of education, were individuals with varying opinions of VAD shaped by societal views, and by personal or professional experience.

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General views held about the practice of VAD

"I believe individual choice, wherever possible, should be respected . . . just as we respect what quality of life means to an individual. We often do not know the circumstances surrounding an individual's choice, whatever that may be . . . who are we to question it"

"Euthanasia isn't for everybody but I believe if there is no cure and your (sic) going to die in pain then it's a self choice"

Choice, control and dignity (30.7%)

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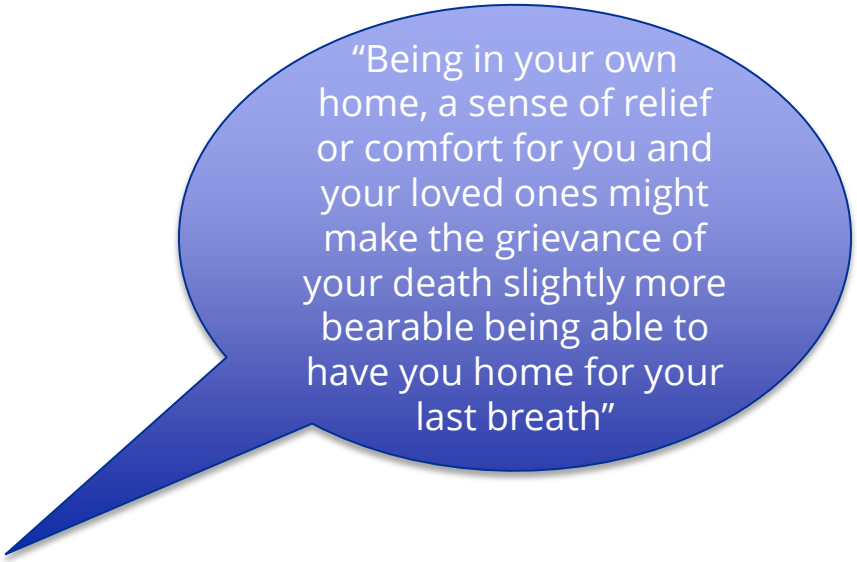
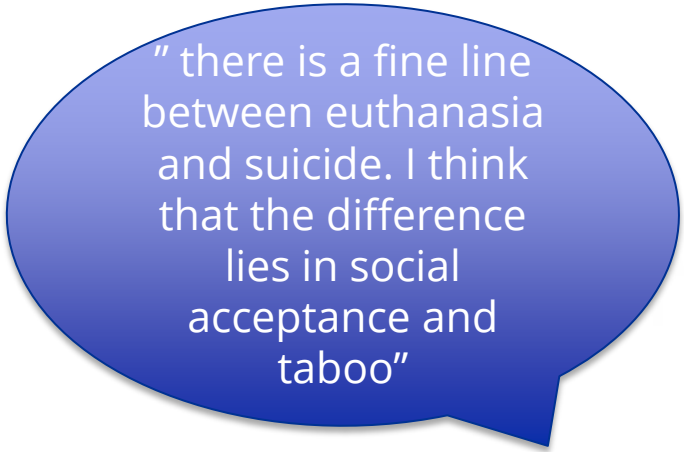


Palliative care and dying at home (11.4%)



Societal factors (11.2%)

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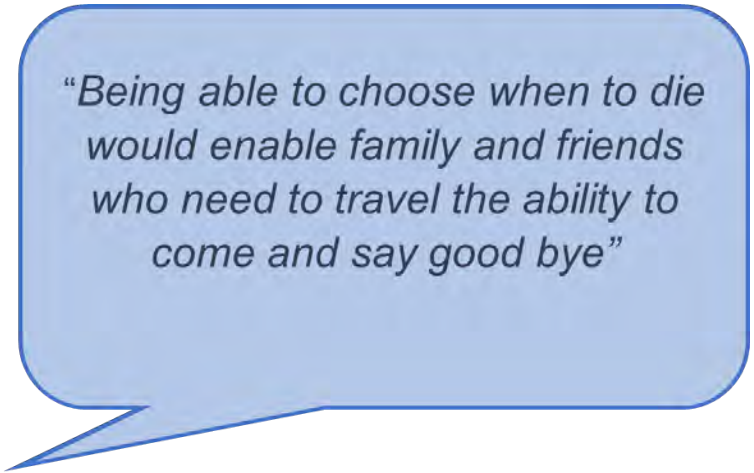
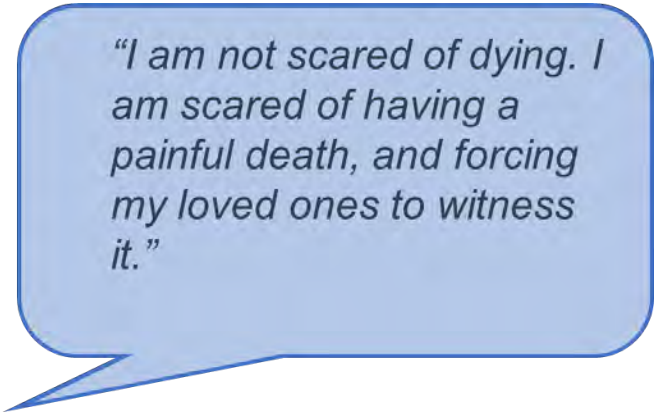


Impact on loved ones (7.5%)



Being in pain or suffering (7.3%)

"I also wouldn't want to keep receiving chemotherapy until the end. However I acknowledge that when it actually happens to you this decision isn't as easy as you thought"

Medical Intervention (7.1%)

"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' (6.3%)

“I also believe that there would be a small minority of society that could or would potentially take advantage of the concept of euthanasia/assisted dying. I think it would need to be heavily regulated”

Laws and regulations (5.5%)

“Legalising Euthanasia in AU will be great, but due to its limits and very stringent rules, it will only benefit some. A lot will still come back to that Advanced Directive”

Advance Care Directives (4.1%)

Case Study 2: Covid, bereavement, funerals

This study investigated 2020 MOOC participants' responses to an online activity reflecting on funerals and memorials during the time of COVID-19.

From this activity, n = 593 responses were received

Of these, n=204 explicitly described funeral experiences and were analysed qualitatively.

2020 MOOC participants were predominantly from AUS /NZ

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Positive and negative reactions

Positive emotional reactions to COVID funeral changes, n=70 (34.1%)

- Gave chance to attend when would otherwise miss out, n=58 (28.43%)
- Increased intimacy of smaller funeral, n=20 (9.80%)

Negative emotional reactions to COVID funeral changes, n=129 (63.24%)

- Limited attendance numbers, n=106 (51.96%)
- No physical hugs /touch, n=61 (29.9%)
- Technology glitches, n=10 (4.90%)
- Impersonal voyeurism, n=19 (9.31%)
- Unable to say a ‘proper’ goodbye, n=57 (27.94%)
- Virtual funeral feels less real, n=36 (17.65%)

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Case Study 2: Covid, bereavement, funerals

“The church live streamed the funeral service so that people could watch it remotely. The nursing home where mum did volunteer work put it on for all the residents up there as they were in lock down”

Positive: Attendance from afar (34.1%)

“It was actually quite lovely as the family were able to focus on each other and their grief, rather than needing to 'look after' all the other mourners”

Positive: Intimacy (9.80%)

“The celebrant had to ask those who were not closely related to leave the building so that the family can come in”

Negative: Limited Numbers (51.96%)

“Hugging is such a part of how we show of support and love, that this affection and comfort has probably been the most distressing element to have restricted”

Negative: Physical touch (29.9%)

“The original time for the online funeral was 10am but due to technical difficulties was played online at 7pm that night”

“Strange, we felt like we were spectators watching on security cameras”

Negative: Virtual glitches (4.90%)

Negative: impersonal voyeurism (9.31%)

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“There was a strong feeling of the farewell being unfinished. We were told that there would be a gathering to celebrate his life sometime in the future, when things were "back to normal" after Covid”

Negative: Proper goodbye (27.94%)

“I felt that I was looking in from the outside and no real connection to what was happening. Funerals always leave me with a certain amount of emotion - this one just left me feeling empty”

Negative: Less real (17.65%)

“the family as a ritual, placed a flower on every chair and spoke the name of the person who would have attended so they were included in the ceremony that was being live streamed. Very touching to witness this”

“i had to think out of the box to have a funeral he deserved […] I brought my dad home where his casket was placed in the front yard in front of his car with all his beloved things around him this way we were able to have all his friends and family drive by to pay there [sic] final respects”

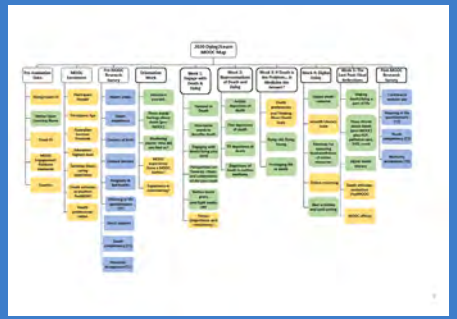
New mourning rituals (13.24%)

“I wonder how much emotions (sic) this will bring up for some people and loved ones, and how COVID19 will affect the way people grieve - from an interactive level, a drawn out / delayed process and in other ways”

“He had to leave that day due to limited flights and his dad was cremated with no attendees or ceremony This has caused a prolonged grief and although my husband was with him when he died, he feels the guilt of not being at his funeral and abandoning his step mother into locked down nursing home to grieve alone”

Insight into the impact on grieving

The power of the platform and the structure



Ability to pivot relied on:

Articulating the issue

Agreeing relationship to the D2L MOOC, participants and the learning activity

Using the capabilities of the system

Dealing with ethics

Being responsive

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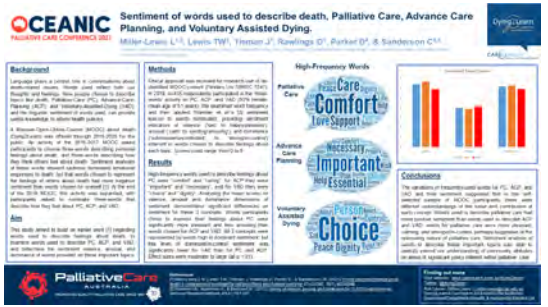
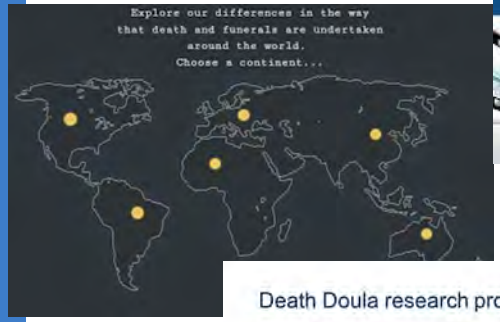
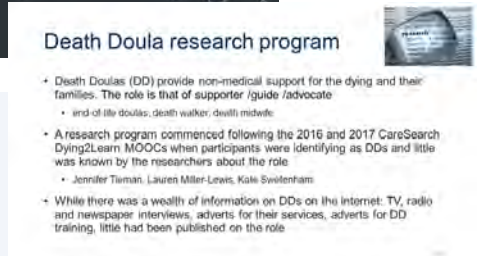
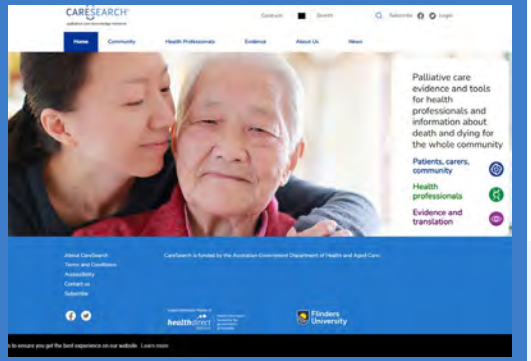
Other elements, studies, and insights







So, what have we learned?



- For CareSearch, Dying2Learn was an experiment, an adventure and a risk but influential
- People are willing to talk about death and dying (and they had a lot to say)
- People of all ages and from all parts of Australia got online
- Participants valued the course
- Participating in Dying2Learn supported attitudinal and behaviour change
- Meaningful data was captured in purposeful and incidental activity
- Digital is an opportunity to share and understand

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But what does it mean for palliative care?

Need to consider how technology and digital can enhance palliative care practice, research and education.

What role can virtual communities play in the palliative care ecosystem?

How can we collect and use incidental and purposeful data around palliative care, death and dying?

We need to map and connect palliative care interfaces (personal, societal, community, health professional, humanity)

How do we support and encourage curiosity, innovation, rigor in our workforce?

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The gift that keeps on giving

Publications:

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CareSearch would like to acknowledge the participants and facilitators of the Dying2Learn MOOCs held in 2016, 2017, 2018 and 2020.

Dying2Learn continues:
www.caresearch.com.au/community.dying2learn
@dying2learn

CareSearch is funded by the Australian Government Department of Health and Aged Care

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