Effect of supportive engagement through Massive Open Online Course participation on death coping.

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Australian Palliative Care Conference 2017
Background: The Challenge of Death

- Death has become excluded from social life.
- Outsourcing has reduced community familiarity with death.
- Can be a hard topic to discuss.
- Makes preparing for death harder.

Fonseca & Testoni, 2012; Gellie et al., 2015
Background: What can we do?

• Public health-promoting palliative care calls for discussion and education about death and dying in the community.
• This engagement may help people accept death, develop skills and competence in active decision-making, make end-of-life wishes known, and support others.

Fonseca & Testoni, 2012; Noonan et al., 2016; Swerissen & Duckett, 2015.
Background: Death Competence

• Death competence is a construct representing a range of capabilities people have for coping with death, as well as attitudes and beliefs about these abilities.
• Includes behavioural, cognitive, and affective components.
• Offers a way to monitor potential gains from death education.
• Research has found that face-to-face death education can improve death competence in health-related settings.
• Not known what effect there might be in the general community.

Brysiewicz & McInerney, 2004; Bugen, 1981; Claxton-Oldfield et al, 2007; Robbins, 1994;
Background: Online learning and MOOCs

• Online learning platforms offer a promising new strategy for facilitating death conversations.
• Online learning strategies offer technologically advanced capabilities for educational interaction, social networking, and sharing knowledge.  
  Massive = accommodate large numbers
  Open = accessible to the general public and often free
  Online = need internet
  Course = learning opportunities
• ‘Connectivist’ c-MOOCs focus on facilitating socially-constructed learning and exchange by using digital environment for forums and peer collaboration.

Hughes et al., 2016
The Dying2Learn MOOC

• Developed on OpenLearning platform and made freely available to the general public.
• Aimed to provide a community platform for social discussion and connection regarding death, dying, and palliative care.
• Experiential focus - stimulating personal engagement, conversations & reflection.
• Learning approach was co-constructive
  ➢ e.g. – exploratory & reflection activities, no ‘marked’ assessment
• Participants viewed as active co-contributors rather than passive recipients of learning.
• Ran in 2016 and 2017 over a 6-week period: introductions, then 4 core modules and a final reflections module.
The Dying2Learn MOOC Core Modules

1. How we engage with Death and Dying
   • No laughing matter? / How we engage with death and dying through language / through public mourning / through funerals

2. Representations of Death and Dying
   • Death and dying via Art and History / through Film / through TV

3. If death is the problem….is medicine the answer?
   • What will we die of / the role of medicine / Prolonging life or prolonging death

4. Digital Dying
   • The web is big / digital legacy / digital access and equity / dying is personal, dying is public
As one of the activities in Dying2Learn, we will be holding a real-time online text-chat with Dr Peter Saul and Dr Christine Sanderson on Wednesday the 19th of April, 7-9pm, Australian Eastern Standard Time. Dr Peter Saul is an intensive care specialist in Newcastle, Australia, and Dr Christine Sanderson is a palliative care doctor and one of the Dying2Learn course facilitators. This will be a great opportunity to ask questions and have an interactive chat, so please add this date to your diaries. (If you need to convert this time into your local time zone, you can use this converter.)
The Present Study

• Explore if engagement in online learning about death had an impact on feelings of death competence in the 2016 cohort.
• Embedded within the MOOC as a formal research study, optional for enrollees to participate in.
• Designed to complement the general evaluation of the MOOC (based on course learning objectives and satisfaction).
• Research Question:
  ➢ “In members of the general community who enrolled in a MOOC on death and dying, was there any significant change over time in death competence between enrolment and the end of the MOOC?”
Study Methods

- Basic Demographic information collected at MOOC enrolment
- Enrolees sent email invite to optional research study:
  - Asked to complete 2 short online surveys
    1. Before MOOC participation (socio-demographic background & death competence)
    2. After MOOC finished (post-MOOC death competence)
- General evaluation and MOOC engagement metrics extracted from platform, eg:
  - percentage of course progress (content accessed & activities done)
  - Number of comments made

Flinders University Social and Behavioural Research Ethics Committee (Project 7247)
Study Methods

Measure of Death Competence: Bugen’s Coping with Death Scale

• Self-report on agreement with 30 statements about aspects of coping with death
  ➢ “I can talk about my death with family and friends”
  ➢ “I am able to spend time with the dying if I need to”
• Respond on scale from 1=do not agree at all to 7=agree completely
• 30 items summed; higher scores indicate greater death competence
• Evidence of validity and reliability

Bugen, 1981; Robbins, 1994;
Study Participants

- 1156 people enrolled in Dying2Learn in 2016
  - 1069 invited to do optional research study
    - 277 (26%) completed death competence scale at baseline
    - 254 commenced the Dying2Learn course
      - 134 completed death competence scale again after MOOC finished (retention rate of 53%)

- Complete case data available for 134 participants, used for longitudinal analysis
### Descriptive Statistics on Socio-demographic and MOOC Engagement Variables, n=134

<table>
<thead>
<tr>
<th>Socio-Demographic Characteristics at Enrolment</th>
<th>% or M (SD)</th>
</tr>
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<tbody>
<tr>
<td>Gender (female)</td>
<td>94.0%</td>
</tr>
<tr>
<td>Age</td>
<td>54.03 (12.1)</td>
</tr>
<tr>
<td>Located in Australia</td>
<td>90.3%</td>
</tr>
<tr>
<td>Self-identifies as a Health Professional</td>
<td>53.7%</td>
</tr>
<tr>
<td>Has a University Qualification</td>
<td>76.9%</td>
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<table>
<thead>
<tr>
<th>Socio-Demographic Characteristics at Baseline</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td>Death experience</td>
<td>67.9%</td>
</tr>
<tr>
<td>Self-Assessed Health ‘very good’ or ‘excellent’</td>
<td>64.9%</td>
</tr>
<tr>
<td>Australian Born</td>
<td>67.2%</td>
</tr>
<tr>
<td>Identifies with Australian Culture</td>
<td>70.9%</td>
</tr>
<tr>
<td>Consider self ‘very spiritual’</td>
<td>32.1%</td>
</tr>
<tr>
<td>Consider self ‘very religious’</td>
<td>5.2%</td>
</tr>
</tbody>
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<thead>
<tr>
<th>MOOC Engagement Outcomes</th>
<th>M (SD)</th>
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<tbody>
<tr>
<td>Total % Progress made in MOOC</td>
<td>65.79 (23.75)</td>
</tr>
<tr>
<td>No. of comments made in MOOC</td>
<td>25.10 (32.36)</td>
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Study Results

MOOC participants at the beginning already felt pretty competent in coping with death.

Death competence scores increased by the end of the MOOC.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>n</th>
<th>Baseline Mean (SD)</th>
<th>Post-MOOC Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death Competence Scores</td>
<td>134</td>
<td>158.23 (26.51)</td>
<td>165.85 (22.00)</td>
</tr>
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Repeated Measures ANOVA: Time effects

<table>
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<tr>
<th>Wilks Lambda</th>
<th>F (df)</th>
<th>p</th>
<th>Partial Eta²</th>
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<tbody>
<tr>
<td>.876</td>
<td>18.89 (1, 133)</td>
<td>.0005</td>
<td>.124</td>
</tr>
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Improvement represented a medium-to-large effect size of practical significance.
Study Results

- Does health professional status or death experience moderate effects of the MOOC?

- No interaction effect found – effect of MOOC on death competence did not depend on health professional status or death experience.
- No difference between occupation groups on death competence, but those with death experience scored significantly higher.
- Significant effect of time; size of improvement in death competence over time substantial.

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<th>Mixed Between-Within ANOVAs Effects</th>
<th>Between Subjects Factors</th>
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<tr>
<td></td>
<td>Occupation</td>
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<tr>
<td>Time*Group Interaction Effects</td>
<td>Partial Eta$^2$</td>
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<tr>
<td>Group Effects</td>
<td>Partial Eta$^2$</td>
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<tr>
<td>Time Effects</td>
<td>Partial Eta$^2$</td>
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Study Results

• Were there any unique predictors of change over time in death competence scores between baseline & post-MOOC? Did specific demographic groups show more change in death competence as a result of participating in dying2learn?

• Multiple linear regression predicting post-mooc death competence scores after adjusting for scores on death competence at baseline. Included socio-demographic and MOOC engagement variables.

• Final Model significant $R^2 = .475^{***}$

• Baseline death competence was a strong predictor of post-MOOC death competence (standardised beta = .59***)

• Only significant predictor of change in death competence was the level of MOOC progress (beta = .20**) i.e., more mooc completion = more competence increased.
Summary of Findings

• Participation in Dying2Learn online was effective in increasing death competence, and magnitude of the effect was considerable.
  ➢ After the MOOC, community members perceived themselves as being better prepared to cope with death in their lives, even allowing for the initial high level of death competence shown at enrolment.
  ➢ Consistent with previous findings.
• Improvements in death competence following completion of Dying2Learn did not vary depending on health professional experience or bereavement experience. The impact was similar for all groups.
• Greater engagement in the MOOC content lead to greater improvements in death competence over time.
Implications

• Dialogue about death in supported online environments may be one useful public health strategy for building death competence in the general community.
• There was a real eagerness to have these conversations and a community of practice developed.
• Online conversations may lead to family and community conversations.
• May lead to being able to share wishes, and being more prepared when death inevitably comes.
• Health professionals are people too – moving from the professional stance to the personal.
Implications

Personally transformative experiences:
• “Discussing death and dying without offending anyone was liberating and has prompted me to get all my ducks in a row.”
• “I found it great for own personal learning and that of my work.”
• “I now feel more comfortable starting death/dying conversations with family, and have started conversations as a result. Challenging myself with this topic has given me more insight into the meaning of life (my own and in general), and I have a greater acceptance of the inevitability of death. Very personally rewarding, even though I didn't really expect that.”
• “The course gave me exactly what I needed – a greater inner awareness and increased confidence to talk more openly about death.”
Limitations and Future Directions

- Self-report survey, not objective observation of death competence behaviours
  - i.e., long-term follow up of behaviours necessary
- Generalisability of findings limited by self-selected nature of the participants, and the sample attrition.
- Lacked a comparison group not exposed to the MOOC.
- Seek verification through rigorous qualitative analysis of MOOC text entries.
- Replication of findings in future cohorts to help unpack influence of MOOC components.
- Need more detailed investigation of impact on different types of health professionals.
Conclusions

- A Massive Open Online Course (MOOC) was a viable strategy for stimulating community discussion about death and dying.
- It was possible to conduct formal research embedded within these online environments.
- First study to show participation in a MOOC on death and dying was effective in increasing death competence.
- MOOC didn’t benefit one demographic group more than another.
- Further exploration is required to determine whether this change in death competence can have a positive impact on participant’s behaviour in the community regarding subsequent death conversations and preparedness.
References


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