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DYING. USING A PUBLIC EVENT SERIES AS A RESEARCH TOOL TO OPEN COMMUNICATION ON DEATH AND DYING

Kate Sellen¹, Molly McGovern¹, Emma MacGregor¹, Karen Oikonen², Maria Cheung²

¹*Design For Health Studio, OCAD University, Ontario, CA*

²*Taboo Health, Toronto, CA*

Abstract

This paper will explore the use of public engagement as a strategy for encouraging and enhancing conversations about end of life through the variety of events that were part of the Dying., a public event series that ran in the 2019 DesignTO festival. Dying. invited practitioners, researchers, artists, and designers to collaborate with the wider community to explore the topic of death and dying. The Dying. series attracted over 4,000 attendees in 2019, 14 speakers, and 12 exhibiting artists. These events included public engagement through interactive exhibit, a public art/design show, public lectures, participatory art installations, participatory design workshops, and evidence-based game playing. Dying. encouraged dialogue among community members and practitioners, initiating non-medical portrayals and expression of experiences associated with dying and death. Part, research tool for knowledge mobilisation, the interactive

exhibits served to engage the public in sharing experiences of end of life in light weight and playful interactions, as well as more heavy weight interactions. Data gathering for research on health topics using participatory public exhibit was part of the research intention behind the design of the exhibits. Dying. opened an interdisciplinary dialogue between designers, medical practitioners, and the public, addressing a need among practitioners for more opportunities to share their work and learn from colleagues, and a need among the public for opportunities to hear and experience a more varied discourse about death (knowledge mobilization). Dying. creatively offered the public multiple ways to engage with the topic of end of life also supplying supporting resources on advanced care planning and other aspects of end of life decision making.

Keywords: interaction design, end of life, participatory research, design approaches

Introduction

Death, and the process of dying, has been seen in more recent history as a medically orientated event. As death more often occurs in medical settings, the circle of those who have experienced death first hand grows fewer (Holyoke et al., 2016). Since death is unfamiliar, many people experience fear and avoidance with the subject of death. It is recognised that one consequence of this is that only a small number of people have considered or written an advanced care plan or considered their preferences for care or end of life wishes (Holyoke et al., 2016). As a large portion of the global population approaches older adulthood, communities have the opportunity to reimagine death and dying, change conversation about death, and encourage advanced care planning. Responding to this opportunity, an interdisciplinary movement towards a more holistic approach to death has emerged through public events, including medical practitioners such as BJ Miller and Atul Gawande, and design studios such as Falmouth University's MOTH (UK), Open IDEO's End of Life project in collaboration with The Helix Centre and Sutter Health (UK). Interdisciplinary interest in this topic is mirrored in the public realm with grassroots events such as death cafés offering the opportunity for dialogue about death in familiar environments. Art and design initiatives have offered reflective and speculative installations such as Hereafter (Barcia-Colombo, 2018) which offers participants services in digital legacy, using 3D body scans and digital reconstruction to curate virtual memorials after death.

Participatory public events, such as festivals, offer an opportunity for a diversity of people to engage in discourse at their own comfort level. A characteristic of participatory events is the use of storytelling and creative self expression to encourage engagement. Festivals are an environment in which engagement is heightened, allowing for

dialogue, and new social positions, in which various social groups, normally separated, come together to build new social realities (Picard & Robinson, 2006). Festivals on death and dying are beginning to occur on a more regular basis around the world. By the nature of the engagement that festivals enable, participatory arts based events are a platform for knowledge mobilization, where ideas and information flows between participants (Kontos, and Naglie, 2007; Rossiter et al, 2008; Cowdell, Booth & Appleby, 2017). Participatory events have the capacity to mobilize knowledge shifting public opinion, even with difficult topics such as end of life.

Dying., was a public participatory event series launched in 2019 in Toronto, Canada. Dying. invited practitioners, researchers, designers, artists, and the wider community, to collaborate on and explore the topic of death and dying through the lens of art and design. Through the Dying. series, interdisciplinary dialogues emerged as medical and allied health practitioners, artists, designers, and the general public shared and constructed a varied discourse on death and dying. In this paper we will explore how Dying. provides a research tool to enable knowledge mobilization, and how, through the variety of interactions that can occur with public engagement at festival events, Dying. contributes to opening communication on contemporary issues on death and dying.

Festival as Knowledge Mobilization

Increasingly, health researchers are expected to meaningfully bring knowledge into practice (Graham, Tetroe & KT Theories Research Group, 2007). As such, implementation science and over thirty frameworks have been developed to support the iterative process from results to mobilization (Graham, Tetroe & KT Theories Research Group, 2007). These frameworks support knowledge exchange along a spectrum of interactions and engagement. Increasingly, knowledge

translation is identified by its focus on the decontextualized, unidirectional flow of information from research to practice (Abma et al., 2017).

A trust-based alternative to knowledge translation is knowledge mobilization. Knowledge mobilization is described as the flow of knowledge between individuals in a highly contextualized, reciprocal relationship (Abma et al., 2017; Cowdell, Booth & Appleby, 2017). Based in part on Friere's work on participatory co-learning (as described in Minkler and Wallerstein, 2011), knowledge mobilization focuses on social interactions to co-create and make sense of knowledge (Abma et al., 2017). The approach recognizes tacit knowledge as essential and the nature of knowledge as emergent inquiry (Van de Ven & Johnson, 2006). It is philosophically congruent with a constructivist paradigm, arts-informed approaches and participatory design (Abma et al., 2017).

Examining Death through Festivals

Festivals offer a unique vehicle for designers, artists, academics and health researchers to engage in knowledge mobilization with members of the public. Festivals produce and mobilize new knowledge relevant to various disciplines, while revealing the complexity of the issues under exploration (Van de Ven & Johnson, 2006). One such example being "Death: the Human Experience" an award-winning public engagement exhibition run through Bristol Museum in the United Kingdom (UK), the festival invited the public to consider ethical and cultural perspectives on death, and their trends over history.

Dying. Festival Theme

Dying. was situated within DesignTO, an annual design festival in Toronto, Canada. The Dying. event series (or festival theme) is an ongoing collaboration between Taboo Health, Ontario College of Art and Design University's (OCAD U) Health Design Studio, and festival organisers DesignTO.

The goals of Dying. are to (a) facilitate dialogue across boundaries in conjunction with moments of expression (b) broaden conversations and scholarship in relation to issues of death, dying and design; (c) make and strengthen connections across disciplinary spheres and practitioners (d) develop embedded and change orientated resources for educators, designers, health professionals and researchers.

To widen the scope of disciplines engaging with Dying., we embraced an arts-informed knowledge mobilization approach, in acknowledging how it may support new perspectives, interpretations and knowledge (Eaves, 2014). We organize the events to support a range of interaction opportunities that align with concepts from knowledge mobilization including: community engagement, creative self expression, storytelling, play, learning and relationship development (see figure 2 below).

In the first installment of Dying., these events comprised 4 main streams of engagements including (1) a public art/ design show, Dying.exhibits, (2) public lectures, Dying.discussions, (3) public engagement through interactive exhibits, Before I Die, and (4) end of life decision making serious game playing, Hello. These are described below:

Before I Die.

"Before I Die" chalkboard wall from Candy Chang's open sourced public art project model (2012), facilitating engagement on end of life for the general public who did not directly attend the Dying. series. The wall was mounted on the exterior of the OCAD U in downtown Toronto. Throughout the week, the wall was populated with hundreds of responses. The "Before I Die" wall served as a lightweight interaction supporting community engagement and creative expression.

Dying.exhibits

Dying.exhibits featured 12 artists and invited participants to think about their

relationship with life and death as a process without polarity. Rather than thinking about death as a period at the end of a sentence, the work exhibited considered death and dying as an ellipsis; an invitation to continue the conversation after what might seem like a natural end. The work within the exhibit portion of *Dying*, probed into conceptual thinking on life as it continues after the event of death; extended through objects, memory, narrative and ritual.

Participatory Installations

DIYing Free

An interactive installation, *DIYing Free* is a Do-it-Yourself Coffin that the public were invited to lie in and take selfies. The coffin is constructed from an openly available cardboard template and made from discarded packing cardboard.

Ellen Snowball's Room 237

An immersive installation, *Room 237* captures the emotions of loss and grief experienced in a recreation of a long term care room, retelling the story of losing a mother to dementia.

Time Moving

Time Moving is a participatory installation which invites the public to reflect on their perception of time during end of life (Paper 1, 2020). The impact of the installation emerges as a tapestry of representations, conversations and perspectives collected together. The installation series continues to investigate temporality during death, and has been extended to explore digital communication and death (Paper from CHI, 2020). *Time Moving* served as a lightweight to heavyweight interaction supporting community engagement, creative expression and storytelling.

Constellations

Constellations is a participatory installation which invites visual storytelling about death and end of life (Oikonen & Hale-Wilkes, 2019). Participants express their experience of death by circling colourful strings around

various pegs. Each peg represents a junction in their story of experience: support systems, perception of preparedness, and their experience of grief unfolding.

Hello - End of Life Game Play

"Hello" is a conversational card game about death, dying and end-of-life. Developed by Common Practice LLC, Hello engages participants in discussions about end-of-life and advance care planning (ACP) through structured participation in small groups (Van Scoy, et al., 2016). "Hello" served as a heavyweight interaction supporting community engagement, storytelling, play, and relationship building.

Dying.discussions

A keynote speaker and mini-symposium were central parts of the *Dying*. series. In 2019, *Dying.*, hosted 14 speakers at the mini-symposium. The event aimed to offer attendees broad perspectives, and opportunities to participate in open conversations about death, dying and design, covering contemporary topics such as medically assisted dying, body disposal and sustainable death practices, death awareness and HIV communication, reflective practice for palliative care, and design of palliative services for those who are housing insecure and who may be street involved. *Dying.discussions* served as a heavyweight interaction supporting community engagement, storytelling, learning, and relationship building. The topics of discussion illustrate the opportunity that such events play to make more visible contemporary social issues.

Results

In this paper we have focused on the structure of *Dying*. 2019, and the framework that describes the structuring of knowledge mobilization through the festival event series as a tool for design researchers in health. If we consider attendance and interaction as a metric of success, *Dying*. 2019 saw over 4000 people interacting in a tangible way with the festival events.



Figure 1: Opening night

The success of Dying. 2019 allowed for Dying. to be held again in 2020 with over 3000 people interacting in tangible ways. In continuing to offer death, dying, and design theme to the DesignTO festival, this work has broader community implications, however. Festivals and large event series can stimulate interdisciplinary alliances between a variety of community stakeholders. Dying. Exhibits saw submissions from over 50 artists and designers. In its second iteration Dying. discussions became Dying.dialogues with over 30 submissions from a range of thinkers, designers, and practitioners, on death and climate change, medically assisted dying, equity and access to end of life care, legacy, and public access to end of life decision support through public spaces were some of the topics discussed.

Discussion

The culmination of the components of Dying. created an intentional engagement opportunity in which participants could

experience a dialogue on death and dying that is different from the dominant medical discourse. In this way the festival nudges social change on issues of death and dying. Picard (2016), suggests that festivals or large social gatherings, can assist in the individual navigating through social changes and transitions. Further Picard (2016), argues that the format of the festival serves as a good vehicle for positioning lived experience within narratives of death and dying. The impact of the festival can disrupt our social beliefs and alter our symbiotic framework when thinking about life stages and transient periods (Picard, 2016).

The variety of events within Dying. allowed for various types of interactions. Playful exhibits and participatory artworks invited the public to explore, and immerse themselves within the work and alternative ideas on end of life. In creating these lightweight and invitational interactions we may have attracted interest from different groups to safely explore ideas of death and dying and stimulate new social narratives

that may have otherwise not arisen. The success of these playful interactions may have permitted extended participation in other components of the Dying. series which had denser more heavyweight interactions involved within them. Thinking

about the structuring of the experience of the Dying. Festival theme, we designed a pattern of engagement opportunities that serve as a framework for knowledge mobilization initiatives expressed here in the form of a matrix:



Figure 2: A framework for knowledge mobilisation activities through participatory engagement

The variance in structuring this event series with diverse levels of lightweight and heavyweight participation created spaces in which interdisciplinary conversations could occur to unearth and mobilize new and tacit knowledge and narratives on death and dying (Anoize, et al., 2014, ; Picard, 2003). The impact of these festivals, as with other knowledge mobilization efforts, cannot be measured by researchers alone (Abma et al., 2017). The outcomes of these collaborations can increase self-reflection and knowledge mobilization within the local community, and stimulate multi-sensory experiences for publics to explore their own ideas and concepts of death and dying.

Conclusion

The Dying. series investigated how multifaceted public engagement(s) like,

festivals and event series can be used to house and cultivate public discourse on death and dying. These events can enrich and encourage new citizen engagement on end of life topics, and situate these dialogues within the public’s routine lives. Dying. nurtured this engagement through a series of open participatory events including public lectures and art shows, evidence-based game play, and outdoor interactive installations. Dying. continues to work on supplementing the discourse on the potential of art and design in end of life, in 2020 the series ran again, and plans for the 2021 season are in place. As this series continues to develop we will continue to open opportunities for public community conversation and interactive experiences on topics surrounding end of life.

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