HCI at End of Life & Beyond

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Ethical Considerations for HCI Research on End of Life: <u>Time Moving</u>

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Abstract

This short paper describes an ethical approach to HCI research through pubic exhibit on the topic of end of life. Drawing on work on ethical considerations for arts related research in health, and the experience of several research projects on end of life, a number of concepts were explored by the researchers to inform the design and implementation of the Time Moving series. Time Moving is an exhibit based research project on temporality, end of life and digital communication. Through the mounting of three separate installations in the Time Moving series, the researchers have encountered ethical considerations and experiences of research creation that benefited from these ethical considerations.

Author Keywords

Arts-informed research; ethics; exhibition; death; dying

CSS Concepts

• Applied computing: Arts and humanities, Fine arts
• General and reference: Document types, General literature

Introduction

There is a discernible movement towards a non-medical approach to end of life, and one that is being reflected in the growing engagement of the design community in work that challenges design techniques and practice.
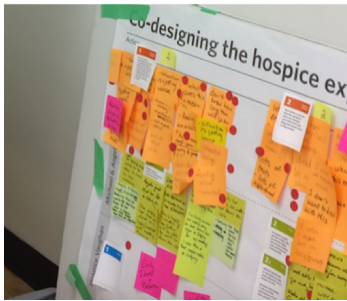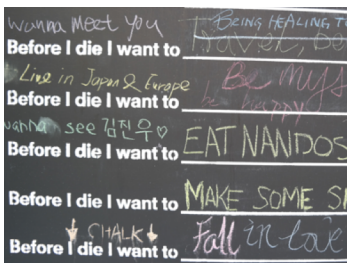
Figure 1: Design process work for end of life game.

Figure 2a and b: Before I die.., Candy Chang, Toronto, 2019.

The Health Design Studio at OCADU has been involved in several projects on end of life and at the intersection of end life experiences and human computer interaction, including sensorial aspects of hospice experiences [5, 8], materialization of end of life preferences [14], communication with remote family members [9], narrative gaming for end of life choices (figure 1) [10], and an ongoing research program on temporality, end of life, and digital communication [15, 16]. More recent work has concentrated on public exhibit on end of life as a vehicle for knowledge mobilization, and knowledge discovery. The *Time Moving* series aims to contribute to the following research questions:

1. To develop and adapt art and design techniques for engaging in research on the topic of death and dying.

2. To understand how communication technologies are used during decline and death

3. To develop further understanding of connection and temporal aspects of death and dying.

Public Engagement in of End of Life

End of life is routinely medicalized [4]. As death more often occurs in hospitals and controlled settings, the circle of those who have witnessed death firsthand grows fewer [4]. Many identify fear and avoidance with the subject [4]. This poses a challenge to researchers exploring these sensitive contexts.

Storytelling is one such way to address this, and, as in many areas of HCI research, this can be undertaken in a range of ways from fully immersive and time intensive, to shorter, emergent, and lightweight ways. In more recent work at the Health Design Studio we have chosen to develop interactive public exhibit as a research vehicle. This was partly inspired by a number

of non-HCI work on end of life including: Holyoke and colleagues' *Reflection Room* [4]. This public exhibit focused on eliciting and mobilizing tacit knowledge about death experiences. Other examples include, Candy Chang's *Before I Die* wall which employs lightweight engagement to invite the public to share their aspirations for before death [1] (figures 2 a and b). This constructivist approach in public space generates sustained reflection in each iteration of the project. From a research perspective, these public exhibits pose unique opportunities as simultaneous data collection and knowledge mobilization vehicles. *Time Moving* builds on these examples inviting reflection on the concept of time, digital communication, and temporal change.

Time Moving

In the design of *Time Moving* our team used an arts-informed approach which supports a constructivist ontology [12]. Our work is more broadly theoretically situated in the tradition of participatory design, constructivism and draws on the prior work of artists and designers who inspire us [1, 2, 4]. *Time Moving* is an ongoing series of participatory art installations, now in its third iteration, with each iteration of *Time Moving* informing the next as knowledge emerges. Participants of past *Time Moving* installations shared their perceptions of the 'shape' of time (Figures, 3, 4 a,b, and 5), reflections on experiences, drawings, diagrams, stories and quotes about their experience of time during end of life.

In its most recent iteration, *Time Moving 3* (figure 6) asks participants: "How do you feel about communicating digitally during times of death?". Abstract representations of time at end of life were

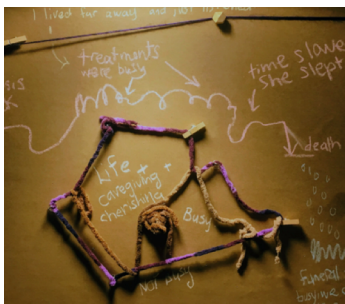Figure 3: Time Moving 1: One of three prompts

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Figure 4: Time Moving 1a and b: Freeform anonymous storytelling.

presented to participants in chalk, alongside the prompt. Black postcards reminiscent of chalkboards were offered to participants, with white gel pens to write their responses. Over ten days, *Time Moving 3* saw 80 postcard responses, in three languages. To close the engagement with *Time Moving 3*, participants were invited to choose a button with a quote or abstract visualization of time. Each button contained a re-presentation of participant's conceptualization of time at end of life, from contributions to a prior *Time Moving* installations. *Time Moving* promotes storytelling, memories, reflexivity, identity (re)construction and personal development, all benefits of arts-informed approaches [3].

Figure 5: Time Moving 2: Open ended prompt, constrained materials.

Figure 6: Time Moving 3: Closed prompt, constrained materials.

Ethical Considerations for Public Engagement

As with any approach, an arts-informed approach to participatory design research poses unique ethical considerations. Engaging with tacit knowledge can induce emotions, and cause difficult or even disturbing sensations [3, 7]. As a team, we are responsible to account for the emotional safety of our participants. Facilitating ethical engagement in end of life design research bears careful consideration. In planning *Time Moving* and other participatory installations on end of life, our team identified the need for an ethical framework for facilitating engagement. Through interdisciplinary collaboration, we discovered a resource from arts-related health research to meet this need.

In their practical guide to arts-related research, Savin-Bade and Wimpenny present twelve ethical considerations: ownership, reflexivity, negotiated meaning, transparency, plausibility, honesties, integrity, verisimilitude, criticality, stance, authenticity, and peer evaluation [13].

As a team, we engaged in discussion and a collaborative activity to synthesize these twelve considerations. The team synthesized the twelve ethical considerations [13] into three ethical principles. We then sorted our project work into the four design phases (discover, define, develop and deliver) and coded each decision according to our developed ethical principles using an online application (Trello). We co-created three ethical principles: co-constructed truth and meaning, iterative co-creation, and reflective, invitational engagement.

Co-Constructed Truth and Meaning

We chose to represent negotiated meaning, plausibility, honesties, verisimilitude and authenticity as co-constructed truth and meaning. This description fit a constructivist epistemology as an interdisciplinary design team, and supported our vision to invite honest, authentic reflection. Specific to *Time Moving*, these considerations prompted our team to prioritize anonymity of participants. No personal identifying information was collected, nor were photographs or video taken of participants engaging in the installation. This principle supported our participants to negotiate their meaning of death and dying alongside others. As a result, *Time Moving* invited reflection on the connectivity of experiences, and provided an output for communicating thoughts, feelings and reflections on end of life.

Iterative Co-creation

Transparency, criticality and peer evaluation together became iterative co-creation. We identified our values in transparency, community engagement and evaluation. In other installation work, we embraced iterative co-creation by collaborating with community members who host or share space with our work. We facilitated information nights and debriefing sessions, interventions shown to support participants in the (re)construction of new meaning [7]. By seeking feedback, we ensure engagement meets participants' needs with integrity and respect. Further to this principle, our team prioritizes sustainability in the sourcing and afterlife of our materials. We strived to choose biodegradable or Forest Stewardship Council certified materials. Following our project work, some materials will be donated to local community programs.

Reflective, invitational engagement

Ownership, reflexivity, integrity and stance were collectively described as reflective, invitational engagement. *Time Moving* was exhibited as a part of a larger indoor exhibit on design for death, in a publicly-accessible community arts centre in an economically mixed urban neighbourhood in Toronto, Canada. As a part of our reflexive stance, we crafted a land acknowledgement statement to include alongside our participatory installations. This is part of our commitment to work towards justice and reconciliation for the damage done by colonialism in the Canadian context. We intended this to respect the integrity of the community we were inviting to participate in our work. In the interest of building relationships, we also integrated principles of non-violent communication [11] into our relational approach with the community. Finally, offering mental health support for participants

is often a recommendation offered by research ethics boards. We decided to proactively offer effective and appropriate resources, building these into the design of materials and structure of the exhibit.

Conclusion

Our design team synthesized ethical considerations for arts-related research [13] into three ethical principles (co-constructed truth and meaning, iterative co-creation, and reflective, invitational engagement). These ethical principles guided our participatory design research on end of life. In so doing, participants at our public exhibits have reported feeling heard, validated, and supported in their sense-making of design for end of life. This experience has developed new ethical perspectives on inviting participatory engagement on emotionally loaded topics in sensitive contexts. Our hope is by sharing this experience, we can contribute to the burgeoning dialogue around ethics in design research with sensitive topics.

Acknowledgements

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