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# TIME MOVING: A PARTICIPATORY EXHIBIT TO EXPLORE TEMPORAL PERCEPTIONS AROUND DEATH AND DYING

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## Abstract

Time Moving engaged in public making of timelines through storytelling utilizing participatory materials with the intention of creating an environment for the public to express and explore temporal awareness. This public experience engaged in questions of disorientation/orientation to time horizons – an integral aspect to decision making and communication at the end of life. Designers may make use of participatory experiences, like Time Moving, to build temporary assemblies (Lindstrom & Stahl, 2014) that facilitate group storytelling conversations, and generate new capacity for expression on topics like death and dying. How time is experienced during moments of death and dying can change as temporal awareness shifts, priorities change, and capacity/physical constraints arise. To engage the public to explore this concept of time and temporal perception at end of life, Time Moving invited response to three prompts: (1) When you think of time, what does it look like? (2) What did time feel like during your end of life experiences? (3) How is dying time different than

living time? Share a story or memory of death in shapes, yarn, etc. More specifically, these questions were asked to gain initial insights into experiences around disorientation/orientation to time horizons and perceptions of end of life. This interaction was designed with the intent of creating a public space for people to share and express their own personal end of life experiences and temporal perceptions, alongside others. Beyond these three prompts, Time Moving also offered supporting end of life materials and resources, facilitating access to local health services outside of the exhibit context. This paper will examine the use of participatory exhibit based approaches, like Time Moving, in generating new knowledge around topics like death and dying, as well as how results from exhibit based research may further contribute to understandings of quality whole person care.

Keywords: exhibit, end of life, participatory research, person centred care



## Introduction

Death and dying is a universal experience, but it is also unfamiliar and ambiguous. Despite the understanding that we will all have experiences with death and dying, public discourse on these subjects remains taboo (Wildfeuer, Schnell, & Schulz-Quach, 2015). These social restraints on death can have broader health implications like lack of preparedness for end of life, emotional strain in bereavement for family and friends, unexpected legal responsibility to close contacts, (Banner, et al., 2019).

The number of older adults is anticipated to increase exponentially over the next 30 years (Bohnert, Chagnon, Dion, 2015). This spike in the population age, foreshadows increased demand for end of life care. The person centred care framework (McCormack, 2003; McCormack & McCance, 2006) provides opportunities for collaboration with designers on these issues. The framework denotes person centred care as subsisting of four distinct constructs: (a) prerequisites of the carer, i.e.: personal knowledge of self and interpersonal skills, (b) the care environment, i.e.: supportive organizational systems, sharing of power and potential for innovation and risk taking, (c) person-centred process, i.e.: shared decision making and engagement, and finally, (d) expected outcomes of persons involved in care in a therapeutic environment of shared decision-making. Participatory design techniques and a constructivist epistemology are congruent with this theoretical approach to health care.

In the case of Time Moving, we consider this work to be an arts-based participatory design exhibit. Arts-based research is defined as inquiry which is committed and immersed in the craft of artistic practice (Eaves, 2014). Arts-informed research, alternatively, is research which uses art as a source of inspiration in source or re-presentation of new knowledge (Eaves, 2014). Either approach offers an opportunity for a constructivist paradigm to flourish (Rossiter et al., 2008).

To investigate death and dying we developed Time Moving, a participatory design exhibit, that sought to examine expectations at end of life and temporal perceptions in circumstances of death and dying. In this paper we will examine Time Moving, how exhibits can be used to produce and translate knowledge on death and dying, and the design implications exhibition based research can have on future methodological approaches in health design research and broader health oriented research.

## Design of Time Moving

Time Moving is a participatory installation series that intends to explore temporal perception in end of life experiences. Time Moving was open to the greater Toronto public for one week in January, during the DesignTO festival. DesignTO is a city-wide event series in which designers and artists celebrate and feature their work in a variety of spaces housed around Toronto. Members of the public are invited to view/participate in numerous design works.



Figure 1: Curvilinear space created by the exhibit structure

Time Moving was assembled using pieces of pre-built furniture to create a temporary engagement space inside an open area at OCAD University in downtown Toronto. The human-scale structures were positioned in a curved floor plan to create a dynamic flow through the exhibit to encourage participants to move through and engage with the materials presented (Figure 1 above). Information panels about the exhibit's themes of time and temporal perception were mounted to one side of the exhibit space, while the prompts and activities were set up on the other side. Lighting was selectively placed to highlight prompts and the associated materials to be used for responding to the prompt, increasing the visual and tactile interest of the exhibit.

Graphic design decisions were made to complement the subject matter and activities in the exhibit. The information panels used sketches from another version of Time Moving as a background to create visual references, with the intent of prompting participants to respond in a similar fashion. The minimalist aesthetic complemented the structural exhibit

pieces in two ways: to create a backdrop for engagement and not draw attention away from the activities; and to create an informal and welcoming space for abstract expressions.

The three prompts of Time Moving were:

1. People have different ways they think about time. Choose or draw a shape that looks the most like time to you
2. There are many ways we experience time in end of life, what did time feel like in your experience?
3. How is dying time different from living time? What does time look like? Share a story in yarn, shapes, etc.

Each prompt was associated with different materials. In the first activity exploring what time looks like, tactile materials included pins, rubber bands, markers, chalk (Figure 2 below) and tulle-like ribbons. Small visual images that conveyed time, such as calendars, hourglasses and clocks were presented as reference. The variety of materials provided options for participants to express themselves, ensuring they had the opportunity to be as representative or abstract as they wished.



Figure 2: Examples of materials available

In the second activity, participants were encouraged to respond to the prompt through writing and/or drawing. The materials used were clothing pegs, cards, markers and pens. Once participants have created their response, the cards are hung on clotheslines within the exhibit structure. We found this activity to be more clear-cut and straightforward than the other two activities in the exhibit.

Finally, the third activity compared dying time and living time, with the prompt encouraging abstract expressions. Similar to the first activity, the materials provided were pins, rubber bands, yarn, markers and chalk. Participants also repurposed materials from the other two activities to express their ideas on the tapestry.

## Results

Time Moving gathered a large amount of engagement with over 100 participants contributing their own lens on temporal disruption in end of life. This allowed for specific inquiries into variances of temporality without losing focus of the broader topic area of end of life. Each prompt within Time Moving progressed into heavier interactions, and created engagements in which participants had to reflect in increasingly complex ways. Staggering the interaction in this way, allowed for a thoughtful buildup on reflection on end of life experiences, and served as a forward for thinking openly about death, dying, and temporality.

In the first phase of the interaction, participants were given a selection of choices to interpret how they viewed time by selecting shapes that were most representative of time. Moving forward, the interactions became more fluid in how participants used the materials. The second prompt asked participants to share an experience of time in end of life, writing on a small postcard (Figure 3 below).

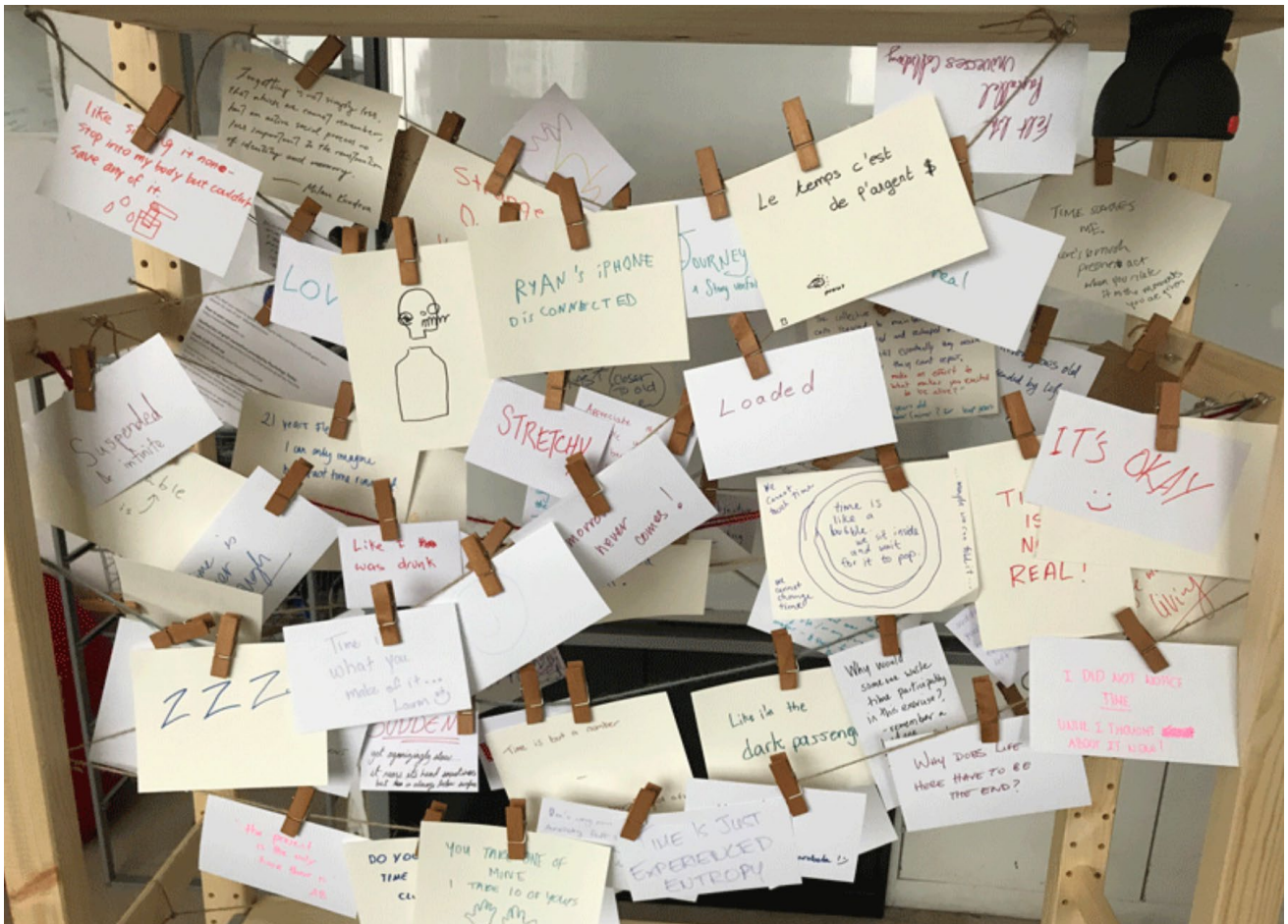


Figure 3: Responses to the second prompt on experiences of end of life

There were no restrictions on how they used the material, or on what types of interactions they chose to talk about. In the analysis we saw the range of responses from this activity where some participants wrote song lyrics, abstractions from TV and movies, others wrote long theoretical explanations, and some offered small drawings. The final prompt encouraged collective making, building a tapestry weaving together various responses (Figure 4 below). In this section, participants were welcome to express their memories as literal or abstracted as they wanted. Some used chalk to draw timelines, marking specific points with narrated explanations, others tacked yarn and rubber bands in amalgam shapes.

Overall, the objective of the exhibit design was to create visual curiosity and interest throughout the exhibit, which invited participants to gather and engage with the

exhibit. The outcome was a collaborative tapestry showing the nuances of temporal perception in moments of end of life. Timelines, memories, considerations, critiques, and images collectively united to create a blended image of the temporal horizons in end of life

Time Moving unveiled various examples of disorientation in moments of dying. Participants created standard timelines showing disruption and confusion in moments of dying, drawing tangled lines and loops representative of these moments. Others created abstract images in the form of drawings and shapes, forming the yarn and elastic bands into various open-ended patterns. Some used words, phrases, song lyrics, and other pop culture references as a representation of how time felt. The result of this work was a larger complex narrative that revealed the multiple co-existing interpretations on death, dying, and time.

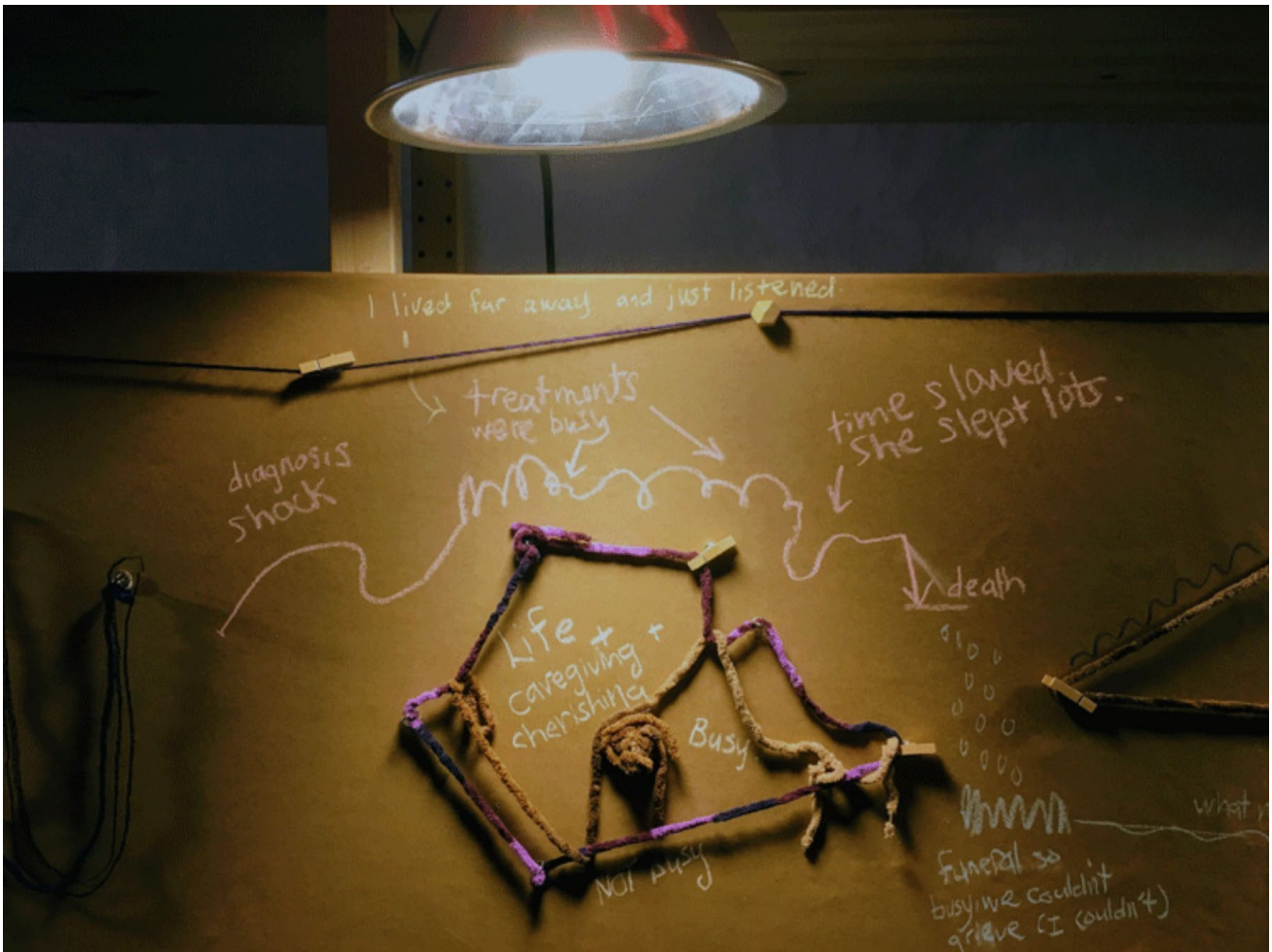


Figure 4: Tapestry

## Discussion

Within Time Moving we saw that the public interacted with the work and redefined traditional experiences of dying to share the temporal ways in which dying influenced their lives. As a result, hundreds of participants explored the fluidity of temporal perception using chalk, yarn, and shapes as an aid in retelling their narrative. The knowledge produced within this work suggests the possible uses for design in end of life, and how exhibition and design can influence decision making in end of life.

Arts-informed and arts-based approaches are increasingly being used in health research (Lapum et al., 2016). This is one way to provide the public with alternative platforms to express difficult or hard to put into word topics, like death and dying. Art-based research can add depth and insight to qualitative inquiries, and can produce

new knowledge that may not have been discovered using a traditional research approach, as well as serve as a vehicle for knowledge translation (Fraser & Sayah, 2011).

In the exhibit “the 7,024th Patient”, health researchers use photography and poetry to re-present interview data collected from people on their experiences of open heart surgery. The exhibit re-presents their contemplations of their mortality, agency and identity. The exhibit was installed at a major cardiac hospital in Canada, and open to all. Follow up interviews with health care providers who attended reported this exhibit enhanced their empathy in practice, supported them to include holistic care approaches, and improved their relational care (Lapum et al., 2016). Yet these participants also reported the context of their care matters: they required

institutional and leadership support to fully integrate these new perspectives in practice (Lapum et al., 2016).

As context of person centred care influences engagement, so too context matters for participatory exhibitions. Time Moving was installed indoors at OCAD University. This meant the participants were mostly members of the university community. Compare this engagement with an iteration of Candy Chang's *Before I Die* (2012) installation, the exterior location affords greater public participation and engagement with this installation may reflect different viewpoints on death and dying, from increasingly diverse backgrounds.

Time Moving, positioned itself as an exhibit that sought to uncover if temporal perception changes in experiences in the end of life. Informing this work was various health sector perspectives, including work from Glaser and Strauss (1968) who explored temporal trajectories in dying. This work continues to influence the post-modern healthcare structure, and deepens the discourse on death and dying in general. Glaser and Strauss (1986) suggest that time has shape and that dying trajectories exist. These trajectories are narrative archetypes of typical dying experiences that occur within acute care. This research has influenced how practitioners engage with their patients about dying. The concept and prompts in the exhibit built off of previous health and design research, and showed the potential of the exhibit not only as a producer of knowledge, but also as a way to translate well established research and interdisciplinary knowledge that otherwise may have been unattainable to the general public.

In the context of health care, people are meant to be active decision makers in their health, yet patients experience a hierarchy of knowledge in a paternalistic health care structure (Rothmann et al., 2016). These structures foster superficial or tokenistic

engagement (Rothmann et al., 2016), at the loss of achieving the processes or outcomes of person centred care (McCormack & McCance, 2006). Participatory design exhibits offer a unique opportunity for people to meaningfully engage and share decision-making about death.

By virtue of this meaningful engagement, participants are able to reflect on their core values and beliefs regarding death. This process allows participants to orient their end of life decisions against these values and beliefs, and to share guiding principles with family and friends who may go on to serve as their substitute decision makers. Time Moving empowers persons and their supports to advocate for the death they want, thus achieving the expected outcomes of person centred care (McCormack & McCance, 2006).

## Conclusion

We have explored how participatory design exhibits can be used to engage with the public in new ways, and may contribute new knowledge and understanding. In hosting our own exhibit, Time Moving, we examined end of life experiences, and how these moments may alter temporal perception. By developing Time Moving, we were able to create a temporary assembly that brought together various social groups to participate in the anonymous creation of temporal timelines and horizons. This work allowed for knowledge creation and mobilization to occur in real time. Many social scientists, artists, and designers (Glaser & Strauss 1968, Copp 1998, Candy Chang) have explored death and dying within their work(s), however, social restraint on these topics remains present. There is a lack of environments, outside of specific healthcare contexts, that host open, fluid, and continuous conversations on end of life (Copp,1998). Participatory exhibits have a role to play in both uncovering and mobilizing knowledge on end of life..



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