

# Constellations: Designing participatory engagement and end of life

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## ABSTRACT

Constellations is a participatory art installation exploring the family experience of end of life. Held in January 2019 at Artscape Youngplace, a community-based arts hub, Constellations was part of DesignTO, a 10-day art and design festival in the city of Toronto. People were invited to select a ball of yarn and weave their experience of death and dying through a series of questions. What emerged was a tactile expression of the universal human experience of end-of-life, honouring individual experiences while revealing patterns in the collective. As one participant shared, “It felt like walking a labyrinth and everyone else’s paths were visible.” At the closing of the festival, the designers removed each string, capturing the data that underpinned the visual patterns. This paper describes the installation and presents the value of creating opportunities for participatory art installations as an approach to engaging the public in conversations about death and dying.

## Author Keywords

Death; dying; end of life; participatory design; participatory art; tactile; design research; public participation; public engagement

## INTRODUCTION

Constellations was part of the 2019 Design TO festival, featuring the ‘Dying’ series that explores the theme of end of life through the lens of design and art. Through participatory and observational experiences, the Series invited people to think about their relationship with death and dying as an individual, a member of a family and social network and as a human being in

society. The ‘Dying’ series is a collaboration between OCAD University’s Design for Health graduate program and not-for-profit organization TABOO Health.

Constellations is a participatory installation that invites people to make a series of selections based on their experience with the death of someone in their social circle. Prompts aim to capture the experience individuals have, being a family member or close friend to a person dying: their relationship to the person dying, others within their network during the end of life period, supportive influences, compromising influences, the level of preparedness the individual and family felt as they moved into the end of life and after death.

People are invited to connect their responses through a single thread, resulting in a tactile snapshot (or map) of their experience. The analog format generates live-data throughout the Festival, culminating in a collection of contributions, revealing patterns of commonalities and anomalies about how end-of-life is shared among family members. People are invited to attach a written anecdote to their thread, providing context to the story that emerges from their responses. ‘Constellations’ provides a discreet way of sharing deeply personal experiences that can otherwise be difficult to share in a society that does not always want to talk about death.

What emerges is a tactile expression of the universal human experience of end-of-life.

## METHODOLOGY

An Application of Participatory Design in Public Space  
Constellations was hosted at Artscape Youngplace, a community arts centre that houses non-profit organizations and facilitates community programming. Each January, Artscape provides space for DesignTO to host festival events. Part of the success of Constellations’ high rate of participation, with more than 200 entries and an audience of thousands, was the association with the festival and multiple festival events (e.g.

opening reception, tour groups). The festival drew a diverse audience, with interests that ranged from health care, art, design, death and dying, in addition to the wide draw of offices and services that are housed at Artscape (e.g. yoga studio, Indigenous arts, children's programming). Additionally, Artscape's programming and services draws people of all ages, and is located in a diverse neighbourhood in Toronto.

#### Installation Construction

The installation was housed in a hallway, fixed to the wall. Using foamcore boards affixed with nuts and bolts, the installation invited participants to use a ball of yarn to respond to questions about their experience of a family member or loved one dying. The installation stood 8' tall and 16' wide, providing space for 12 questions:

- What was your relationship to the person who died?
- How long was the person sick before they died?
- Who was providing support for the dying person?
- How far away were you from the dying person?
- What was your role in supporting the dying person?
- What kinds of things did you do to support them?
- What other responsibilities did you have?
- Who was part of your support network?
- What was the most supportive or challenging during this time?
- How long were you aware that the person was going to die soon?
- How prepared was the family for death?
- What support did you have after the person died?

The final weaving experience asked people to choose words that completed the sentence 'The family experience was...' from a list of words that included: beautiful, chaotic, disorienting, planned, angry, divisive, exhausting, unifying, relieving, guilty, stressful, peaceful, accepting, loving, lonely, reflective, respectful and an open space to add a tag with another word that describes the experience.

The questions began as simple, factual answers (e.g. the relationship to the person that died) and progressively became more reflective, sometimes warranting multiple answers to a single question (e.g. aspects and degrees of preparedness for the death, words to describe the experience). The layout of the text and nuts and

bolts would be single vertical lines where one answer was appropriate, or circles, where multiple answers could be appropriate. This layout ensured that the string could easily and visibly connect to the suitable answers.



**Figure 1. The first two pieces of yarn added to the installation expressed the designers individual experiences with the death of a parent.**

As participants used their yarn to connect their responses, the yarn created a pattern of lines, as if a constellation in the sky, visualizing their unique experience. As responses collected, the individual experiences layered, as if a collection of constellations in the sky. The black backdrop was a nod to the night sky, contrasted against the colourful yarn. There were also tags available so participants could add context or notes on any part of their experience. Some people choose to write a message to the person who died, others added detail to a node along the path.



**Figure 2. Installation detail as yarn was added to the wall and patterns began to form.**

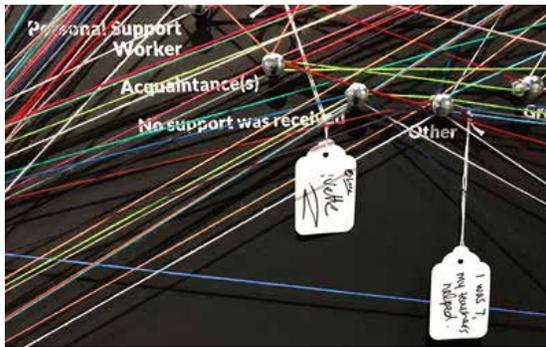


Figure 3. Detail of hand-written tags added to the installation.



Figure 4. The installation growing with yarn as participants continue to add their experiences to the wall.

### Data Collection

Data from the responses was carefully collected during the disassembly of the installation. As each string was removed, the responses were logged in a spreadsheet for synthesis and analysis. By the end of the two-week installation, the installation was so dense with yarn that following individual threads was time consuming and at times too difficult to fully untangle. Logging each individual entry provided the opportunity for more in-depth synthesis.



Figure 5. Rewinding each piece of yarn to capture the data.

While the in-depth synthesis is still in process, early patterns emerged based on placement of the yarn. These include:

A number of experiences took place when the participant was in high school (ages 14-18 years old)

Many participants cited having less than 24 hours where they realized death was close. While we do not have data on what the cause of death was in these experiences, it was a striking trend and led us to further questions.

It was clear that people provided support in many ways, even if they did not consider themselves a caregiver

People found support from many different sources, including those outside the traditional family unit

People expressed having to uphold many different responsibilities while also experiencing a loss

People often selected descriptors that were in tension highlighting the complexity of the end of life experience when considering the broader family experience

### Honouring Each Entry

Upon completion, it was clear that participants often shared very difficult and deeply personal experiences around loss and grief. Moved by this, it felt inappropriate to dispose of the yarn that was stretched across the wall. Instead, the yarn, whether whole lengths or pieces of the whole, were carefully collected. Some participants also wrote on tags and attached to their yarn, sharing additional details on their experience. These lengths of yarn and corresponding tags are currently in the process of being knit into a comforting textile piece. For so many, wrapping oneself in a blanket provides soft comfort and warmth. The textile will provide the soft comfort and warmth, but from others that have experienced similar loss.

### Successes of the Installation's Application

#### Providing words when expression is difficult

Grief from the loss of a loved one, whether a family member or friend, someone whom one had a positive relationship with or one that was more difficult or estranged is often challenging to process, share, or express. By providing words and options for participants to choose, and the option to add words by attaching paper tags, Constellations relieved participants of some of the 'heavy lifting' of sharing an experience with language. This success suggests that for topics that are difficult to process and express, providing opportunities to engage that do not depend on finding the words ourselves, while still providing a source of reflection to process and make sense of an incredibly difficult experience.

#### Tactility and beauty draw participation

Beyond providing words to facilitate expression, it seemed that part of Constellations success and high participation was due to the tactile nature and the beautiful result of the layered constellation entries. Based on feedback and observations, it was clear that participants were drawn to the tactile experience and keen to engage with it. On a busy opening night, attendees waited their turn to claim their ball of yarn and share their story. One participant threw the remaining yarn to the floor in anger, once he finished weaving his story and others stood looking back at their contribution to the in quiet reflection. As the festival went on and the entries grew numerous, Artscape Youngplace regulars would share their appreciation for how the installation evolved, taking on new and beautiful forms and the growing pile of yarn at the base created a punctuation for the collective experience. Throughout the festival, it was clear that the installation's tactility and beauty was a draw for participants and passersby alike.



**Figure 6. Detail of balls of yarn at the base of the installation. Each ball represents an individual experience added to the installation.**

Furthermore, the series of questions were based on the structure of a survey. Constellations demonstrated that a powerful way to draw interest and increase engagement is to create an inviting, thoughtful and accessible experience that people feel drawn to. Based on observations and feedback, the tactility and beauty of Constellations was a large part of what attracted such a high response rate and positive critique.

#### Meaningful exchange between researcher and research participants

While Constellations was not a full research study, instead straddling the lines of participatory art and design, public engagement, and design research, the goal was to prompt dialogue on an avoided, yet universal experience. In this context, similar to a research context, it is important to consider what the value exchange is for participants.

Through observation and feedback, participants shared that the experience was moving, reflective, and sometimes therapeutic. People were grateful for their personal experience with the installation, as well as its effect at uncovering an often hidden and challenging topic. The experience of unwinding their yarn as they reflected upon the questions was one that people expressed gratitude for, and presents another form of meaningful exchange between researchers and participants.

#### Learnings from the Limits of the application

Limited experiences represented in the options provided

Over the duration of the installation, there were moments that revealed the options to questions did not represent all experiences of death and dying, thus excluding some people from participating fully in the installation. Specifically, people who had experienced losing a family member due to suicide did not feel the installation made space for their experience and one participant shared their reaction that "this isn't for me". Additionally, those who lost a family member through medical assistance in dying (MAID) did not see their experience represented in the options provided. Both suicide and MAID are death experiences that are often even more hidden, even stigmatized or avoided, than the broader topic of death in general.

Hearing of these unintended blind-spots within the installation was difficult but also important to acknowledge. This demonstrates the challenge of capturing all potential experiences when answers are provided. The questions and answers were generated based on the personal experiences of the designers, including

previous academic research on the family experience of end of life. While attempts were made to reach beyond experiences similar to those of the two creators, it was difficult to do so fully.

### **Exploring Challenging Topics through Participatory Form**

Key elements of challenging topics that are well suited to participatory form

Part of Constellations' success was that it was well suited for the participatory format, which is not the case for all topics. For Constellations, the challenging experience (death of a family member) was also a universal experience, yet difficult for many people to properly process or share given the challenging nature of the topic in society today. This means that it is something that can apply to most people, and something that a lot of people may be eager to express and share, in a low risk, non-medical, accessible way. Topic areas that fit this formula may also be well-suited to this format.

Death, dying, and end of life explored in a participatory and public form

Death, dying, and end of life are oftentimes taboo topics and difficult to process or discuss. Yet, they are also universal. Everyone will encounter the loss of someone close to them and will have first-hand experience with death and the grief that results from deep loss. Striking conversations on death and dying through the lens of art and design was the goal of the Dying series as part of DesignTO.

The goal of Constellations was to move the topic of death and dying out of hushed conversation and into the public spotlight. Maintaining sensitivity (e.g. local resources and supports for grief were provided) and anonymity of each entry, provided a comforting and reflective opportunity to share that experience. The result was a vast collection of experiences, a powerful indication that given the opportunity to engage on their own terms, people want to explore their experiences with death and dying, and in doing so, can feel less alone.

Opportunities for further application

Based on feedback received during the exhibition, it became clear that this approach is also well suited to scenarios where potential participants are underrepresented and/or have unmet needs.

Particular examples where we received interest in another iteration of Constellations include:

A teacher trying to support a student losing their parent who was reluctant to discuss the experience

An opioid community worker who sought a way to

give a voice in a respectful and approachable manner to those who had addictions and had lost friends and community members due to overdose

A palliative care nurse who wanted to explore how to engage family members of those in palliative care in sharing their experience with the death of a loved one

Coronavirus: timely opportunity for participatory art and design

Since applying and being accepted into the Participatory Design Conference 2020, the world has come to a halt, with Coronavirus sweeping the globe. As hospitals find themselves under immense pressure to keep up with demands while sorely low on both essential and basic equipment, people are instructed to stay home, often without work or pay. Anxiety and fear across society has risen, both for the uncertain wellbeing of ourselves and our loved ones, and for the uncertain impact this pandemic will have on our lives and lifestyles. It is difficult to know when our lives and routines will return to normal, and what this new normal will look like. And what will have to happen before that can occur.

We are currently in the midst of a universal experience that is difficult to make sense of. Covid-19 has forced death into public awareness. There are startling numbers of deaths increasing daily. Articles about advanced care planning, has become top of mind for so many. Health professionals find themselves at a loss of how to support patients, facing a lack of knowledge about the virus and a lack of basic supplies to manage it. Long-term care homes have quickly become overwhelmed, with limited space, staff, or supplies to adequately address the virus for their vulnerable residents. Sick individuals and their families are wrestling with decisions when there are limited good options: take a chance on a hospital, when ventilators are not guaranteed, family cannot join, and the prospect of dying in isolation is very real.

While the virus is shared among us all, impacts take on very different forms, based on so many variables: those on the frontlines or staying home; those earning an income or incomes that have come to an abrupt halt; those otherwise healthy and reasonably safe or unwell for other reasons and thus vulnerable and at risk; those feeling support and togetherness in the community or the recipient of unfair and adverse racist discourse. We are in the midst of one of the most widely shared and uncertain experiences in generations, making it rife with potential to explore through participatory form.

Making sense of this massive loss we are experiencing is made more difficult by new statistics and numbers across headlines every day. As designers that look to participatory art as a means to make sense of events and circumstances, the format of Constellations puts both the individual story and a view of the whole at the focus. We need both to make sense of what is currently unfolding.

While participatory art and design is perhaps more needed than ever, just what form that takes is still very much at the top of our minds. Our usual modes are not available to us in this case, not until public gatherings are permitted again. As practitioners, this scenario challenges us to ask what does that mean for participatory design and art? How will our practice evolve? What can we do to express the things we want to express, when a physical experience is not an option? For now, we do not have answers, but are considering these questions, eager to leverage the clarity and insight we know participatory art can provide.

## CONCLUSION

The final co-created installation was powerful: a beautiful evolving expression of the stories and experiences of so many people. Constellations demonstrates the power of participatory art to facilitate dialogue and exploration around death and dying, a topic that is difficult to discuss and yet universal to us all. This combination made for an inviting and approachable format to the public, drawing 200 participants and hundreds more passersby, to consider and make sense of one of the most deeply human experiences we encounter in our lives.

This format shows that bringing difficult, yet universal, experiences into public space, in a respectful and thoughtful form, can be a powerful tool to share and support navigating challenging circumstances. The need for this has become all the more evident, in recent weeks and months, with the exponential spread of coronavirus throughout the world. Across the globe, societies and individuals alike are feeling the difficulty of death and dying viscerally. Participatory art, albeit with a rethink of its physical form, offers meaningful support at this time where we are finding ourselves challenged to make sense of this historic moment of loss.

## ACKNOWLEDGMENTS

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