Designing More Inclusive Death and Grief Cultural Practices and Rituals

Abstract

How might we better prepare for death and grief in western culture? We are all going to die. Death is inevitable. Yet something that is so absolute, so tangible, and very much a part of the human journey, feels so detached. In the West, dying has been institutionalized, and death and grief have been sequestered, removed from everyday life and community. This has led to an unfamiliarity not only with death, but the grief that follows it, including how to talk about it and how to give or ask for support. Further, what was once the responsibility of loved ones through caring, charity and support, has transformed into a costly field of experts and specialists. These issues: institutionalization; privatization; environmental impact; and high costs associated with death and grief, are outcomes of modern ideologies. They are social issues that merit being challenged, prodded and reflected upon. This major research project surfaces current understandings and troublings around contemporary death and grief rituals in Western culture, and use system archetypes, causal layered analysis and speculative design to explore alternative, more desired futures around death and grief.

Acknowledgements

What a journey! This has been a long, challenging, lonely and beautiful process, and I'm so happy it's done! Exploring how we might make death and grief practices and rituals more inclusive has been life-changing and I want to acknowledge my amazing community that helped me along on this journey.

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Introduction

"Life is the ensemble of functions that resist death."

— Xavier Bichat, French physician, Physiological Researches on Life and Death, 1815

We are all going to die. Death is inevitable. Yet something that is so absolute, so tangible, and very much a part of the human journey, feels so detached. As far back as I can remember, the topic of death has always been taboo and uncomfortable.

I have always felt discomfort engaging in authentic and/or meaningful discussions with others on the topic of death and grief. When someone close to me died, or when someone close to me lost a loved one, the feeling of the experience was always the same: unprepared, unsure of what to say and do. Words have failed me beyond classical acknowledgements of "I'm sorry for your loss" or "my deepest condolences." As brilliantly portrayed in an episode of the comedy show *Baroness Von Sketch*, I have also found myself googling what to write in a card to someone who has just lost someone they love (Young, 2016).

WHERE THIS JOURNEY BEGAN: A TRANSFORMATIVE SHARED SACRED SPACE

My journey of beginning a more intentional exploration of death and grief began in 2012 when I experienced the Temple at my first time attending Burning Man, a week-long counterculture art and music festival that takes place in the Nevada desert each year (Bateman, 2015). The festival was built on a set of principles including radical self-expression, radical inclusion, and a gift economy. Over 65,000 people from all over the world attend each year. In the centre of the experiences at Burning Man is the Temple (Langley, 2012). It's the one place where everyone can go to have a shared solemn experience at any time throughout the week.

This Temple (Figure 1) provided me with one of the most spiritual, connected spaces I have had the opportunity to experience. Throughout the week, Burning Man attendees fill the space with mementos of loss, sadness, grief, and hope. People will look at things that other people have shared, or simply sit quietly, either in a group or alone. The inclusive,

Figure 1: The Temple, Burning Man, 2012
Image source: http://templeguardians.burningman.org/temple-history/img_7345/

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shared, public display of grief and support planted a seed in me that has been growing ever since.

WHY TALK ABOUT DEATH AND GRIEF?

"Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak."

— Harvey Chochinov, testimony before the Subcommittee to Update "Of Life and Death" of the Standing Senate Committee, 2016

Well-being

I want to be able to better support my partner, friends, and family when they face grief, yet there are very limited cultural understandings and resources and I often feel that I don't know how to confidently and comfortably go about it. I stress and stumble over my words, unclear of whether I'm showing enough support. I want to know how to show up for others. The cultural norms I have grown up with feel inauthentic to the human experience.

I want to understand if confronting this mystical topic of death might provide some lightness, or perhaps clarity, when I experience the loss of a pillar in my life. As an only child with just my parents around—my dad's side of the family is dispersed throughout Canada and the United States, and the majority of my mom's relatives live in Colombia—I feel woefully underprepared for the day they die. The same goes for my partner and his family. As a first-generation Canadian with the majority of his family in Bangladesh, how do we ensure that we can have a shared understanding of the practices and rituals needed to hold space for each other?

Finally, how might embracing and making peace with the certainty of my own death change the way I live and exist in the world?

The Dehumanization, Commodification and Exploitation of Death and Grief

Death rituals often call for high-priced services and goods, fueling a multibillion-dollar funeral industry of chemical embalming, fancy caskets, casket liners, grave markers, and expensive cremation urns. The average cost of a basic funeral in Canada is almost $10,000—almost half the annual income of a full-time Canadian worker earning minimum wage, an average of $23,000 (Employment and Social Development Canada, 2019).

Mental health supports—such as grief and bereavement counselling—are not covered by public healthcare plans, adding an additional burden, especially to lower-income families. According to Karen R. Cohen, the Chief Executive Officer of the Canadian Psychological Association, the average person will see a real and lasting absence of grief symptoms after 20 sessions costing up to $4,000 (approximately up to $200 a session) depending on the province and location (Cohen et al., 2019).

At a time when more people are choosing and/or want to choose more eco-friendly death practices, the cost of these options is still often prohibitive and inaccessible. For example, a company called Coeio offers an environmentally friendly "unique" Infinity Burial Suit (Figure 2) which costs U.S. $1,500 (approximately $2000 Canadian at the time of writing this paper). In fact, most stages of dying, death, and grief are now commodified and costly.

Figure 2: Infinity Burial Suit
Image source https://theplaidzebra.com/die-mushroom-suit-will-stop-body-polluting-planet/

Why are we—as individuals, as a culture—ill-prepared for one of the most difficult times in our lives? Like birth, death is a significant event; yet it is one people rarely prepare for, let alone discuss. Western society's inability to explicitly engage with the topic of death before a death occurs complicates the already painful, heavy process of loss and grief. Often those grieving are preoccupied with the logistics of dealing with death, reducing the time and attention they need to mourn their loss. Further, a lack of cultural acuity about death and grief leaves many people uncomfortable with how to console the grieving. This in turn can leave the grieving person with a lack of support—adding additional stress, which can lead to a variety of physical and emotional issues, such as depression, anxiety, trouble sleeping, and feelings of anger and bitterness.

This lack of support exacerbates challenges for anyone who may require additional interventions to help cope with their grief. People with mobility issues may not be able to access certain services. The cost of certain therapies or activities can be prohibitive for many. For many people, these barriers can lead into a spiral of loneliness and/or social isolation.

Figure 3: Funeral home checklist
Image source: https://www.loveliveson.com/funeral-costs-the-essential-checklist-2/

Grappling with the death of a loved one is stressful. All the questions and choices can be so daunting that the bereaved are often overwhelmed. To try to capture the essence of the cost of death, a quick online search turned up an example of a typical extensive funeral home checklist (Figure 3). Further, *A Guide to Death Care in Ontario* (Figure 4), a consumer protection guide put together by a legislated organization of the provincial government, The Bereavement Authority of Ontario (responsible for administering provisions of the Funeral, Burial and Cremation Services Act, 2002), attempts to offer some clarity on the process of handling a death (Bereavement Authority of Ontario, 2019).

While the Guide is nicely designed, it is very text-heavy, long and too vague to give readers a complete picture of all the logistics that need to be considered when a person dies. It was hard for me to go through it when not I was not in a state of shock and grief. I could not imagine trying to read that whole document while trying to determine what I need to do to ensure a smooth end-of-life process, either for myself, or when dealing with the loss of a loved one. Further, for those who may want to undertake more family-led death tasks, it is troubling that the guide states "that institutions, like hospitals or nursing homes, may not
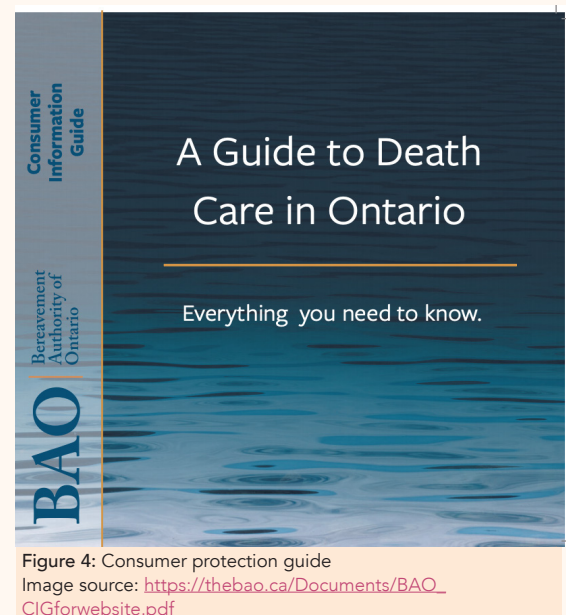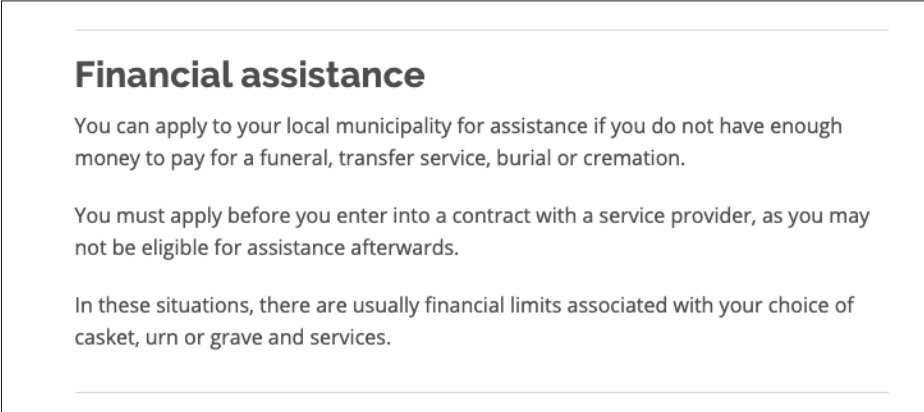
Figure 4: Consumer protection guide
Image source: https://thebao.ca/Documents/BAO_CIGforwebsite.pdf

be aware that it is legal for family members to provide funeral services for their dead family members" (Bereavement Authority of Ontario, 2019). How can they not be aware of something that could add so much unnecessary stress to families?!

These difficulties can be further amplified by systemic and structural barriers built into government policies that don't consider the impacts of dying, death and grief. While caregiving has been recognized both at the provincial and federal level as a time employees may need to take off to care for a dying loved one, it comes with cumbersome rules, paperwork, and delays. Time is not always afforded to those supporting the person dying and/or the dying person themself. Further, there are very particular stipulations around qualifications. For example, in Ontario "family members for whom a caregiver leave may be taken" is limited to only traditional family relationships such as spouses, siblings, children, grandchildren and grandparents.

In Ontario's Employment Standards Act, "employees have the right to take up to two days of unpaid job-protected leave each calendar year because of the death of certain family members. This is known as bereavement leave." ("Your guide to the Employment Standards Act: Bereavement leave | Ontario. ca," n.d.). When there is financial hardship the government does offer support (Figure 5), but there is still paperwork to be filled out. This can add yet another hurdle of frustration and stress.

Financial assistance

You can apply to your local municipality for assistance if you do not have enough money to pay for a funeral, transfer service, burial or cremation.

You must apply before you enter into a contract with a service provider, as you may not be eligible for assistance afterwards.

In these situations, there are usually financial limits associated with your choice of casket, urn or grave and services.

Figure 5: Arrange a funeral, burial, cremation or scattering page, govenment of Ontario, 2019
Image Source: https://www.ontario.ca/page/arrange-funeral-burial-cremation-or-scattering

This is not just a critique of these policies, but more so to call to action to reflect on how these policies do not serve Canadians both for the lack of humanistic considerations, but especially in a changing economy. Canada's current trends toward a gig economy increasingly puts workers into precarious work situations. For example, I currently work for a major hospital institution full-time; but I am on contract, with no benefits and no paid time off.

According to Statistics Canada, in September 2017, 2.18 million Canadians were categorized

as temporary workers and many of the caregiving benefits only extend to workers eligible for Employment Insurance—which does not include temporary workers. Further, these policies are only focused on enabling caregiving support when someone is close to death. These policies need to be revisited, taking into account the modern human experience of what family is, and how death and grief actually affect a person's life.

Environmental Impact of Modern Practices

Mainstream death practices, such as cremation and embalming, are harmful to the environment. A cremated body uses as much energy as a 500-mile car trip, releasing carbon dioxide and other pollutants into the atmosphere (Doughty, 2016). Formaldehyde, one of the main chemicals used in embalming practices is toxic, and once the body decomposes, the chemicals seep out into the soil which create a risk to the local ecosystem. Further, many bodies that are cremated are embalmed first to accommodate a body viewing. When these bodies are cremated, they are still filled with dangerous embalming chemicals (Coutts, 2018).

Living in a Pluralistic Society

My hometown, Toronto, is considered one of the most culturally diverse cities in the world, with about 49% of the population born outside of Canada (Statistics Canada, 2016). This diversity has thrived in Toronto and other pockets of Canada by allowing for pluralism which, according to the *Global Centre for Pluralism in Canada*, is the toleration or acceptance of multiple opinions, values and theories ("What is pluralism?", 2017).

This cultural acceptance has encouraged people of diverse cultural and religious backgrounds to embrace and share their practices of dealing with death and grief. Some groups still follow long-held rituals, while others have moved on to new traditions—or none at all. This has left some people facing a lack of ritual and support during one of the most difficult times of their lives. As rituals and practices have changed over time, "society in general seems to find it hard to be alongside those who have experienced a bereavement" (Walter, 2010).

Since the late 1970s, a number of cultural markers and laws, at all levels of government, such as the Canadian Charter of Rights And Freedoms, include rights, such as," freedom of conscience and religion,"which have helped enable diverse groups to coexist more comfortably together (Canadian Charter, s 2(d), 1982). Yet, there has been no significant investment in Canada in creating inclusive places for diverse groups to share space to address death and grief.

Diversity brings with it different cultural, spiritual and/or religious practices and belief systems. Some groups have established houses of worship where they can build and support community; others find

shared space to express their spirituality. Some groups have no established spiritual space. While the places that are available may be beautiful, grand, and inviting, they are still exclusive. Participants are expected to subscribe to a particular belief system.

For centuries, people often lived in more homogenized communities with similar belief systems. Religion and places of worship were expected to provide many of the things needed to prepare for death and support the grief process. While the enduring traditions of the world's major religions acknowledge loss, suffering, and sorrow as inevitable aspects, and offer the bereaved some forms of rituals for grief and mourning, many people feel disconnected from rituals they grew up with, or find it harder to relate to them in a more modern world.

The Challenges of Futile Care

Futile care is continued treatment given to a patient that adds no benefit to the outcome of a patient's health, often placing a greater burden on the patient and/or the family. It was designed to provide guidance about the extent of care and the reasonableness of discontinuing complex therapy that might prolong life without any possibility of ultimate recovery (Parmley, 1996).

Futile care is distinct from euthanasia because euthanasia involves active intervention to end life, while withholding the latter does not impact the natural course of death (Cassidy & Blessing, 2008).

Yet, medical futility has been conceptualized as a power struggle for authority between physicians and patients and their families, because many times patients and/or their families cannot accept the grim reality that they are dying, and demand increasingly aggressive, invasive and futile care at the end of life. William W. Parmley, MD, former Editor-in-Chief of the Journal of the American College of Cardiology, provides an astute perspective of this difficulty:

> Unfortunately, this principle frequently puts the medical care giver at odds with the family, who may demand certain forms of therapy despite the expectation of marginal or no benefit. "I want everything possible done for mother," may salve a child's guilty conscience but is unrealistic in today's healthcare environment. On the other hand, we see families sometimes going to court to remove life support therapy when hospitals have refused to do so. Beginning with the Karen Quinlan case in 1976, these instances have highlighted our ambivalence about death and dying. (Parmley, 1996).

Since this writing almost 25 years ago, not much has changed. This excerpt below is from a palliative care nurse who responded to a social media posting about death education.

"I'll tell you as someone who works in palliative care 9 years running, we don't (have death education)! Most of the population require assistance with Power of Attorney documents in the moment. Not all, but most of this population is greater than 60 years old, many with families. Many people chose to deem their greater than 90 year old ailment ridden (non-palliative) loved one to be coded on and kept alive (invasively and painfully, and bone shatteringly) with each tick of the health-continuum clock, until they come to us and then insist that the meds used to calm the suffering are at fault for the death they are ever trying to evade and conquer like we're immortal. Our culture is horrible at preparing for death which has come to 100% of humans in history.

Source: Facebook post by palliative care nurse in response to a question about death education, 2019

Research Question

How have social practices preparing for death and grief evolved in modernism and what design opportunities emerge to transform these practices?

Sub-Questions:

- How might we use end-user experience to guide the principles of design?
- How might the design process and methods help to identify a system intervention point to create more inclusive ways to engage with death and grief?

Objectives of this Research

In the past few decades, Western culture has turned away from centuries of human practices and rituals that aided in supporting and managing death and grief. These modern issues—the institutionalization, privatization, environmental impact, and high financial cost of death and grief—are the products of modernity and its ideologies.

The purpose of this research is to explore current understanding and uncertainties about death and grief rituals in Western culture, and to discover and identify opportunities to design more inclusive Western death and grief practices and rituals. In order to do this I will:

- lay out past understandings and musings on Western death and grief culture, specifically in and around acknowledging, engaging with and/or discussing death;
- use lived experience perspectives to help identify opportunities to create more inclusive Western cultural death and grief practices and rituals;
- provide an avenue to honor and amplify the lived experiences of those who have endured the death of a loved one as a way to provide insight and guidance to influence future interventions; and
- offer alternative and more relevant futures of practices and rituals for dealing with death and grief through the development of a speculative prototype.

THE DESIGN RESEARCH PROCESS

Designing the Research Study

Design Research: This type of research focuses largely on understanding the people for whom we're designing, often referred to by the term *end users*. Design research provides different approaches and strategies to solve existing challenges. For me, it is fundamental that solutions should be designed with the end user, and/or leverage the perspective of people with lived grief experience.

Design Thinking Process: The research followed a design thinking process which uses a developmental approach to improve assumptions, understandings and results of the research. The process is the analysis of the relationship between people and products and people to others (Brown, 2009). This helps to inform the understanding and scoping of the problem, providing new insights into alternative solutions that may not have been apparent with a previous level of understanding.

Lead Users: The design thinking process also shows the value of looking at lead users—in this case, someone who has experienced the loss of a key figure in their life (von Hippel, 1986). The goal of this process is to understand the motivations and problems that are amplified for lead users and to understand how those problems would manifest in the needs of regular users. The decision to interview people who had lost someone they would describe as a foundational person in their life (a pillar) was pertinent in learning from the experiences of those who had experienced deep loss and grief, and those insights could then help to reflect on current cultural practices and rituals.

METHODOLOGY

Research Paradigms: Epistemology & Ontology

A research paradigm is defined as a "set of common beliefs and agreements" shared by research-ers regarding "how problems should be understood and addressed" (Kuhn, 1962)

- **Ontology** is the nature of reality (Hudson & Ozanne, 1988)
- **Epistemology** is the relationship between the researcher reality: "What do you know?" and "How do you know it?" (Juliet, 2018)

My methodology follows an interpretivist approach. My interview and study process took a hermeneutic (strongly interpretive) approach, drawing out authentic and essential experiences and recognizing individual lifeworlds and their deep cultural understandings.

The methodology contains three main parts. The context is contemporary Western (Canadian-focused) culture. The design of the qualitative research provides a "snapshot," an analysis of the manifestations of the culture at the time of the research, and the findings and insights derived through that process.

Desk Research: Desk Research was a necessary function during all phases of the project. It was essential to learn what had been done in the past regarding the subject matter of this study to gain a broad understanding of the field. It provided the historical background that supported the understanding of the current cultural context. It was also the means to identify relevant experts in the area of investigation who later became necessary references for the research.

Literature Review: The literature review study included books, journals, research studies, and media articles that broadened my perspective on the subject of contemporary death and grief rituals from a Western cultural context. This research allowed me to better understand key discussion points and who was engaging in discussions about death and grief.

As the research involved human participants on a sensitive topic, a Research Ethics Board approval was sought and approved by OCAD University's Ethics Committee for Research Involving Human Subjects prior to entering any field work.

Expert Interviews: Upon completing a preliminary literature review, I conducted a series of five semi-structured expert interviews of people working in fields related to the death and grief industry. This helped to develop the research scope and provide context of the death industry from the professional observations in their respective fields. This included a known leading death and dying designer working in the healthcare space, a death doula, an end-of-life game designer, and a professor exploring the intersection of social issues such as death through speculative and critical design. The expert interviewees were based in Canada, the United States, and England; all of the interviews took place on the phone or via video chat.

Participant Recruitment: Participants were recruited through postings to my extended networks via email and posts on social media platforms. Participants self-selected to be involved in the research through an online registration process. Within 48 hours the survey had amassed 30 responses and had to be closed down. Interviewees were determined and selected based on a combination of:

- Availability within the interview timeframe
- Deep interest in the social and cultural practices regarding death and grief rituals
- Lived in the current Western cultural context
- Comfort with in-person interviews on the topic of death and grief
- Comprise a diverse group based on age (18 and up), gender, ethnic, religious and socio-economic backgrounds to include a range of cultural and social perspectives to be represented.

Participants were invited to select one of the quiet spaces I offered in which to have the interview, or their home; three of the four opted to host the interviews in their homes. One of the interviews was hosted over the phone as we could not meet in person.

Hermeneutic Interviews: Participants were interviewed in a hermeneutic interview method to interpret the meaning of everyday lived experiences (Lindseth & Norberg, 2004). Participants were invited to talk about what comes to mind most readily in relation to death and grief rituals; the interviewer guided the discussion rather than leading it. The participant-driven dynamic allowed the data to be uncovered in a more naturalistic manner, providing a loose framework to understand the interviewee's perspective more deeply, rather than structuring the content or presuming the focus.

Characteristics of Participants

Participant	Gender	Age	Loss
#1	Female	30-39	Parent
#2	Female	50-59	Husband; Daughter
#3	Female	60-69	Father; Wife
#4	Male	30-39	Unborn child; Grandfather

The key areas of focus explored in the interviews and shared by participants were their personal experiences regarding the tragic loss of a person they identified as a pillar in their life, perceptions of current Western cultural practices and rituals to support death and grief, and their desires for changes—alternative futures regarding death practices and rituals.

Participants were invited to talk about what came to mind most readily in relation to death and grief rituals. In this way, the dynamic allowed the participants to drive the structure and focus of the discussion, limiting researcher assumptions. I acted as a guide, taking cues from the participant as the interview ensued (Vandermause & Fleming, 2011), allowing the data to emerge in a naturalistic fashion. If the participant became unduly anxious or uncomfortable, I exercised judgment as to whether a particular line of inquiry should be pursued.

Notes were captured on plain brown craft paper that was placed in between myself (the interviewer) and the interviewee, who usually sat across a table. This allowed for the interviewee to see what was being captured and as a less distracting way than me taking notes on a computer or in a notebook where the interviewee could not see the notes. At various points throughout the interviews I checked in with the participants to gauge their comfort level with the questions and with the format of capturing the notes.

Informed consent forms were provided prior to the interview so that participants could review them in advance. At the start of the interview and workshop I reviewed the consent process, emphasizing the benefits and risks associated with participating in the study, that participation was voluntary, and that they had the right to withdraw at any point during the interview. After the explanation, the participants signed their consent forms, and thus began the interviews.

Participants received a thank-you email by the next day for their participation. This email underscored the benefits of their contribution and also indicated that the participant would receive a link to the final report upon its completion.

Affinity Mapping: Affinity mapping helps to visualize research-backed insights, observations, requirements and needs on individual sticky notes, "so that the design implication of each can be fully considered on its own. Notes are then clustered based on affinity, which form into research-based themes" (Hanington & Martin, 2012). This type of thematic analysis strives to identify patterns of themes in the interview data. One advantage of thematic analysis is its flexibility. This method is useful both for explorative studies as well as for more deductive studies.

To analyze and synthesize the data, I began with a spreadsheet filled with statements of the original data. From there, the data was written on sticky notes (Figure 6) and through the process of affinity mapping, themes were organized, helping to garner insights.
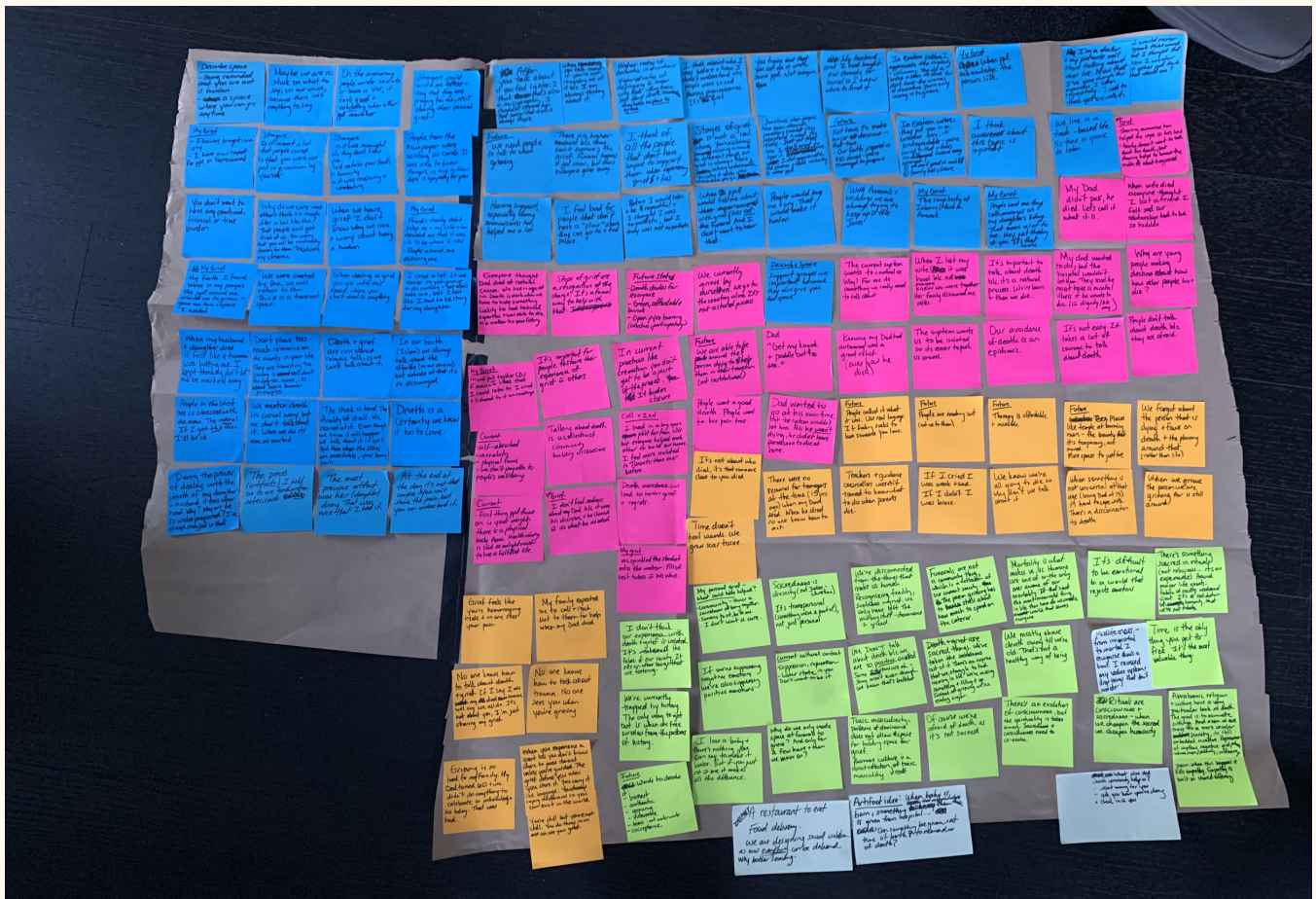
Figure 6: Affinity mapping the collected data

I had several clusters of themes, revealing a larger narrative of the prominent issues raised through the research process. And it was through these dominant themes and ideas that I came to articulate the findings and recommendations of the project.

Causal Layered Analysis (CLA), developed by Sohail Inayatullah, is a method of analysis which accounts for "various streams of causality operating in unison upon an issue" (Ramos, 2003). It allows for the deconstruction of "conventional metaphors," thus enabling the "articulation of alternative metaphors" which "become a powerful way to challenge the present and create the possibility of alternative futures" (Inayatullah & Milojević, 2004).

Its utility is not in predicting the future but in creating transformative spaces that will accommodate the creation of alternative futures. It is based on the understanding that current social practices are fragile, "not as universal categories of thought" (Inayatullah, 1998).

CLA posits that different stakeholders see and experience the world at different levels of reality and at different time scales of change. The four levels that CLA assume are:

- **Litany (time scale: continuous):** The official unquestioned view of reality, the day-to-day view of how things are. While the litany is *the tip of the iceberg*, the layers beneath it allows for different perspectives to be revealed.
- **Systems (time scale: years):** The systems perspective is concerned with systemic causes, including social, technological, economic, environmental, political, and historical factors and explains the behavioural rules behind the litany.
- **Worldview (time scale: decades):** The deeper, unconsciously held ideological vision that supports and legitimates the systemic causes.
- **Myth/metaphor (time scale: civilizations / societal):** The unconscious emotive dimensions of the issue, the gut/emotional level experience of the worldview under enquiry. The language here is less specific, more concerned with evoking images, with touching the heart instead of reading the head. It is not uncommon at this level for social archetypes, stereotypes, myths, untruths and cultural stories to emerge related to the issue being investigated (Bishop, Dzidic, & Breen, 2013).

"Moving up and down layers we can integrate analysis and synthesis, and horizontally we can integrate discourses, ways of knowing and worldviews, thereby increasing the richness of the analysis" (Inayatullah, 1998). CLA allows for the inclusion and representation of different levels of reality and ways of knowing. CLA accepts all perspectives as valid, and by surfacing different and often divergent perspectives, it is possible to see how an issue has been defined more by perceptions and myth rather than by reality (Conway, 2012).

For this research, CLA was used to find both the current value sets and myths underlying the current systems, as well as to create pathways to more desired futures. It allowed me to investigate, understand, and reflect on how more unconscious narratives shape our current realities, and it

provided a clearer way to realize how to reach more desired futures regarding death and grief.

To begin the CLA, data collected from desk research, expert interviews, and participants was coded according to its corresponding layer. This involved reviewing the data and relating it to a specific layer which provided a specific frame of reference (Bishop et al., 2013). This was then followed by clustering themes in each layer. While I was able to develop some initial insights, I followed this analysis with a second pass of organizing and theming the data. Inspired by Jananda Lima's work, *Through the Eyes of the Marginalized*, on the future resolution of oppression of people living in Rio de Janeiro favelas, I followed a similar approach to the CLA for aggregating analysis into meaningful trends and issues. Data is organized across several categories, allowing the visualization of the tension between forces in the problem area (Lima, 2019).

The theming, vertically across layers, allowed for further deconstruction of the issue and also started to more clearly reveal tensions in this research. While each "layer provided specific frames of reference" helping to guide the analysis, the thematic analysis across the layers provided contextual depth and richness (Bishop et al., 2013).

Figure 7: Setup of living room space for workshop participants

Workshop: After the initial analysis, one participatory design workshop was hosted with five participants who had expressed interest in participating in this research and had familiarity with the Causal Layered Analysis method. The workshop design used a combination of methods such as collective brainstorming and storytelling. Through the use of dialogic and generative design methods, the workshop helped enrich the CLA analysis, helping to uncover a deeper understanding of existing cultural worldviews and myths.

The format and locations of the previous participant interviews informed how I would carry out the workshop. Given that most of the interviewees requested that the interviews be held in their homes, I decided it would be best to carry out the workshop in a home setting, in a semi-circle formation in a cozy living room (Figure 7). Food, snacks and tea were provided for participants when they arrived and throughout the duration of the workshop.

The workshop design used a combination of methods such as collective brainstorming and storytelling. The attendees were presented a brief overview of the context and background of the research, followed by the initial findings and concepts of the Causal Layered Analysis. They reflected and shared their own personal experiences and tensions regarding death and grief. This

was followed by a generative group discussion about the content of the CLA, which was then followed by the participants being inspired by a combination of their personal shared experiences, and insights and principles derived from the participant interviews, to create headlines of desired and alternative futures regarding death and grief.

Similar to the participant interviews, all of the workshop participants expressed gratitude for being able to participate in a discussion about death and grief.

Systems Map: System archetypes help to describe common patterns of behaviour within a system, and they make time an explicit variable. As renowned systems thinker Peter Senge notes, in systems "certain patterns of structure recur again and again" (Senge, 1994). They are effective tools for beginning to answer the question, "Why do we keep seeing the same problems recur over time?" (Braun, 2002). For the purpose of this research the system archetypes were used as diagnostic tools, reflective of the underlying structure of the system being studied "from which both behaviour over time, and discrete events emerge" (Braun, 2002).

The outcomes of the CLA led me to include a system map to gain a broader, clearer and more holistic understanding of the tensions identified in the CLA. Although not initially considered part of the research methodology, three system archetype maps were formulated to visualize the tensions revealed in the CLA, providing a conceptual pathway to help identify points of intervention for the proposed speculative prototype.

Speculative Design: A speculative design approach was used as a way to develop a speculative prototype. It can be used strategically to avoid unhelpful consequences and actively shape preferable futures. In itself, speculative design aims to shift perceptions of norms, instead of "reproducing and reinforcing" them (Johannessen, 2019, p. 1). Starting from a What if? a designer is able to investigate social and ethical issues existing in a hypothetical scenario. While speculative design may have limited methodology available for designers who want to conduct it, as well as also often being limited to tech, it provides enough of a framework to push beyond the boundaries of cultural norms and challenge longstanding issues of power and ideologies. Anthony Dunne and Fiona Raby, known for popularizing speculative design, argue for the vital importance of creating objects that function as questions, as protagonists in social fictions. They theorize that the future is fabricated and built, and that the future could be otherwise, if its designers envisioned alternatives (Dunne & Raby, 2013).

As with design fiction and other speculative modes of intervention, speculative design focuses on the development of a discussion, rather than the realization of a product.

STUDY LIMITATIONS

Geographical representation: Given the geographical constraint of the project, three of the participants were from Toronto, Canada and one was living in the United States.

Time and resource limitation: Additional time and funding could have made it possible to interview more participants. More time and funding also could have facilitated the development and testing of multiple speculative prototypes. The proposed design principles and prototype developed are only a first design iteration and they will require additional testing to refine and develop.

Participant sample size and diversity: While the interviewees all represented different ethnic backgrounds, there was limited gender representation as three of the four interviewees self-identified as women. Diversity of participants can facilitate broader demographic representation. Similarly, participant age range was limited: two of the four participants were in their 30s and all the participants were above the age of 30. Further, the reach of the study was limited to individuals within my network.

Context: The outlined findings reflect the Western cultural setting of our study participants, and as grief customs can be culturally specific, their relevance beyond this context requires further research.

SCHEMATIC REPRESENTATION OF THE RESEARCH METHODOLOGY

(Adapted from Pacini, 2017; Bishat, 2017)

Process	Questions	Method: Primary	Method: Secondary
Discover (Problem Finding)	Why don't we as a Western culture engage with death and grief? What can past literature show us about why we are here? What issues are people in the field identifying?	Expert Interviews	Literature Review
Define (Problem Framing)	What can we learn from end users and experts on how to deal with death and grief?	Participant Interviews	Literature Review
Develop (Solution Finding)	How can we better understand the narratives that shape our current realities? How can a more holistic approach to looking at the problem create pathways to alternative, desired futures?	Participant Interviews Workshop	Literature Review CLA System Archetypes
Deliver (Prototype Selection)	Who is the audience of this prototype? What are the trajectories at different levels in the system?	Speculative Prototypes	Literature Review Windtunnel through CLA

Setting the Context

RESEARCH SCOPING

There's a great deal of literature on the topic of dying, death, grief, and bereavement. Yet most of it focuses specifically on the experience of the person dying, or on quality improvement to practices in the public healthcare system or the private funeral industry. The literature search yielded limited published research that actually examines how our culture engages, understands, and prepares for death and grief. Further, the literature uncovered in my search presents the perspectives of experts or professionals in the sector, with a primary focus on the currently accepted modes of dealing with death and grief—rather than a re-evaluation of our whole approach to this inescapable aspect of our lifecycle.

Multiple systematic searches in Google Scholar and the OCAD library had limited findings on conclusive results. The only one related to the focus of this research examined optimal care for bereaved persons, and it could not identify consistent patterns of treatment benefits among interventions (Forte, 2004).

BACKGROUND: LOOKING BACK TO LOOK FORWARD

"Is it not for us to confess that in our civilized attitude towards death we are once more living psychologically beyond our means, and must reform and give truth its due? Would it not be better to give death the place in actuality and in our thoughts which properly belongs to it, and to yield a little more prominence to that unconscious attitude towards death which we have hitherto so carefully suppressed? This hardly seems indeed a greater achievement, but rather a backward step . . . but it has the merit of taking somewhat more into account the true state of affairs…"

— Sigmund Freud, Reflections on War and Death, 1918

There are a few key Western-focused cultural retrospectives that aim to encapsulate the attitudes and behaviours prevalent in our society today. They each have their limitations and represent particular perspectives, but they help to draw a picture of what got us to where we are today.

Ernest Becker, an American cultural anthropologist, wrote the culmination of his life's work, *The Denial of Death*, about humankind's inability to acknowledge our own mortality (Becker, 1975). Becker asserts that "the idea of death, the fear of it, haunts the human animal like nothing else," and that human behaviour's main motivation is the need to control our basic anxiety, "to deny the terror of death" (Becker, 1975).

He believed that as humans, we are the only animal conscious of our inevitable mortality and that our mortality scares us because we are aware of it. Becker concluded that "it is hard for a man to work steadfastly when his work can mean no more than the digestive noises, wind-breaking, and cries of dinosaurs—noises now silenced forever" (Becker, 1975).

In his book, Becker theorized that people developed "hero-systems" like religion because they provide the opportunity to avoid the finality of death by making us a part of something eternal, which then gives our life meaning. However, he acknowledged that "in the age of reason" religion-based systems only work for some people, and science-based systems don't "fill the void" (Becker, 1975).

An interesting phenomenon Becker points out is the power the dead body still holds over the living—even in places less subscribed to faith-based practices and more subscribed to scientific-based understandings. He highlights how societies such as Russia (at the time of his writing) still found significance in what mummification represented. He observes that the Russians "resorted to improvements on ancient Egyptian mummification techniques to embalm the leader of their revolution" (Becker, 1975).

He notes that Russians

> ...could not let go of Lenin even in death and so have entombed him as a permanent immortality-symbol. Here is a supposedly "secular" society that holds pilgrimages to a tomb and that buries heroic figures . . .No matter how many churches are closed or how humanistic a leader or a movement may claim to be, there will never be anything wholly secular about human fear. (Becker, 1975).

Becker concludes with claims we need new illusions but leaves the reader with no further answers— only ideas of what they should seek (Becker, 1975).

In more recent times Thomas Laqueur's book *The Work of the Dead: A Cultural History of Mortal Remains* (2015) revisits this idea of the corpse and its symbolism, inside and outside the confines of religion. Laqueur suggests "our relationship with the dead is the corpse becoming an icon, a way of making something present and tangible that is not present (a memory), a soul subsisting somewhere"

(Laqueur, 2015). There is not a culture that doesn't ritually care for the dead (whether buried or left out for vultures to eat) (Brosens, 2016). Laqueur points out that there is a universal feeling that "there is something deeply wrong about not caring for the dead body;" that the uncared-for body is culturally unacceptable; and that we as a people have "cared for the bodies of their dead since at least 10,000 B.C." (Laqueur, 2015).

Laqueur suggests that this obsession with the burial of the dead and what they represent "is perhaps the fundamental phenomenon of becoming human" and that "the work of the dead is to make culture and set the boundaries of our mortality" (Laqueur, 2015). He states that "living bodies do not have the same powers as dead ones," and that the dead remain active agents in this history even if we are convinced, they are nothing and nowhere" (Laqueur, 2015). He finds that the history of the dead body is the "greatest possible history of the imagination" and that "we endlessly invest the dead body with meaning because, through it, the human past somehow speaks to us" (Laqueur, 2015).

Like Becker, Philippe Ariès wrote his renowned book *The Hour of Our Death* (1981) at the culmination of his life. Ariès also acknowledges the need for meaning, but through a more cultural lens. In his book, Ariès looks at death practices and rituals over the last 1,000 years, from the Middle Ages to the late 20th century, and identifies four general shifts in Western death mentalities, moving from the "Tamed Death" to the "Forbidden Death." This meant moving from a time "when death was communal and eminently public in character" to a time when death became more private with no natural community able or willing to deal with it (Ariès, 1981).

Ariès identified how drivers such as individualization, secularization, urbanization and the advancement of natural science influenced many of the changes in rituals and practices taking place in the "domains of death" (Jacobsen, 2016). For example, Ariès highlights the changes in burial customs, disposal practices, and the planning, use, and appearance of cemeteries over time. Further, he describes how in the past death was embedded in the fabric of community, providing some form of "meaning-making" where the person dying and the family would go through the rituals of death collectively, providing autonomy and dignity to the dying based on their wishes. This increasing "deritualization" was further influenced by the use of time-saving and minimalistic ceremonial practices and rituals such as cremation instead of burial (Ariès, 1981).

In the 20th century, Ariès points out how these changes continued to influence a changing relationship with death as it became, "hidden, invisible, marginalized, and sequestered" from human experience (Ariès, 1981). Aries states that this modern shift equated death with disease "which needed to be concealed in the rooms of clinics" (Ariès, 1981). This is further illustrated in

an excerpt from the book *Illuminations.*

> In the course of modern times dying has been pushed further and further out of the perceptual world of the living. There used to be no house, hardly a room, in which someone had not once died…Today people live in rooms that have never been touched by death, dry dwellers of eternity, and when their end approaches they are stowed away in sanatoria or hospitals by their heirs. (Benjamin, 1969).

People increasingly started to seek comfort, hope, and meaning from medicine when confronted with death and incurable disease, while technology overtook the role of ritual. This "institutionalization of dying removed death from public sight" and "its medicalization went hand in hand with its privatization, institutionalization and professionalization" (Jacobsen, 2016) and the priest was replaced by the doctor as the "master of death" (Ariès, 1981). Ariès pointed out the shift from religion and eternal life after death, "beyond bodily existence," to the more modern investment in medicine, fitness and health, to secure a bit of immortality. It's almost as though, if we have nowhere to go after life, we might as well try to live forever (Ariès, 1981).

Ariès also perceived how the changes of cultural practices and rituals around the death of others also influenced how people approached mourning. He speculated that socially accepted expressive mourning practices and rituals became "the source of embarrassment and inefficiency" with cultural expectations to "keep cool even when confronted with death and loss" (Jacobsen, 2016). "The bereaved is crushed between the weight of his grief and the weight of social prohibition" (Ariès, 1981).

Ariès' work has been both revered for its breadth of covering such a wide range of time and criticized for "defending a nostalgic yearning for yesteryear," providing a one-sided, likely narrow view of past death and grief practices and rituals (Jacobsen, 2016). While his lack of citations makes it difficult to fully understand the context of his speculations and assumptions, his work has been influential in Western cultural discourse, specifically in academic research.

In 2016, Michael Hviid Jacobsen brings a more contemporary perspective to death in Western culture. He thoughtfully and critically considers Ariès' work and proposes that death is no longer hidden or forbidden; it's actually shifted to a new stage—the "spectacular death" (Jacobsen, 2016). He proposes this new stage because "death, it seems, is all around us" and he describes how "spectacular death thus inaugurates an obsessive interest in appearances that simultaneously draws death near and keeps it at arm's length—it is something that we witness at a safe distance with equal amounts of fascination and abhorrence, we wallow in it and want to know about it with-

out getting too close to it" (Jacobsen, 2016).

In his paper, Jacobsen introduces five dimensions of this "spectacular death":

1. **Death Is Visible:** Death is a regular occurrence in the media—in the news, on television, in film, online—yet we don't engage with it or actually personally encounter it. He goes on to demonstrate examples of how we "witness death through images of victims of warfare, disasters or terrorism" which are "now made instantaneously available to a global audience...through the screen of the television, computer or mobile phone" (Jacobsen, 2016). This observation by Jacobsen highlights current social norms, especially this cultural obsession that pokes at the subject matter of death through hyper-provocative images which both overwhelm and entertain us at the same moment.

2. **Death Is A Business:** Death has become so commercialized and costly that it denies the most economically vulnerable of our society dignity during this difficult time. Further, death products and services are easily marketable since "death is frequently used as a source of entertainment in many parts of contemporary popular culture" (McIlwain, 2005). Jacobsen adds that "death is therefore not only turned into a spectacle through the media; it is also used as a means to increase sales and the rapidly inflating costs of burial services" (Jacobsen, 2016).

3. **Death Is A Ritual:** Jacobsen also reminds the reader that "we should not forget the re-ritualization of death," such as more personalized funeral requests (Jacobsen, 2016). The way he describes it is not so much of a re-ritualization, but a response to a gap in the current system. What I find more compelling is Jacobsen's assertion that something is indeed happening right now, with other responses to gaps in the system such as "death cafés, memorial walks, and angel kits for the dying and their relatives, as well as the observation of Halloween as a newly ritualized and commercialized Day of the Dead," (Jacobsen, 2016) a Mexican observance and a relic of the Roman Catholic All Saints' and All Souls' Day (Brandes, 1998). But, these are only temporary spaces and experiences. What might a more permanent acceptance in our culture look like?

4. **Death Requires Decisions:** Jacobsen examines the "palliative care revolution," which gives the dying and their families more control over the end stage of life. He observes that this increased awareness of patient rights provides some additional dignity to death beyond the sterility of hospital walls—addressing one of Ariès' key concerns about how we deal with death (Jacobsen, 2016).

5. **Death Deserves Attention:** Jacobsen observes that "death has gradually developed into a topic of academic attention and specialization, intellectualization", especially since the 1990s (Jacobsen, 2016). He notes that it has taken a long time for death to become a household topic in the discipline of sociology and that there is a steady growing body of information on the subject.

Like Ariès, Jacobsen noted how the "privatization and banning of mourning" from public life "became problems needing to be solved in private or with the assistance of skilled professionals," and asserts the implications of this show how "the dying and the bereaved came to experience the unbearable burden of loneliness" (Jacobsen, 2016).

Jacobsen concludes wondering whether "spectacular death" will shift the way we engage with the topic of death, "to hide, shun and deny death," while acknowledging that death is "one of the most daunting and difficult tasks with which humanity has to deal" with (Jacobsen, 2016).

Atul Gawande, an American surgeon, writer, and public health researcher, also addressed the implications that have unfolded since both Ariès and Becker wrote about death, by declaring in his book, *Being Mortal*, that the medical system has focused on the wrong things. He observed that "we value time on earth more than we value quality of life" (Gawande, 2014).

Gawande highlights how the cultural avoidance of the topic of death in the West has led to the issues concerning the lack of preparation for death, lack of dignity for the elderly, and the failure of medical care "to meet the needs and desires of those facing death" (Gawande, 2014). He says that part of this is due to a low number of certified geriatric doctors, and that this low level of empathetic end-of-life care is exacerbated by the shallow depth of training of our medical professionals. He observes that "97 percent of medical students [in the United States] take no course in geriatrics" (Gawande, 2014).

Gawande (2014) also asserts that the reverence of elders has been replaced by the worship of the independent self. This self-worship has led to obsessions with happiness, youth and health, and has dominated western societies, leading to the marginalization of those facing old age, decay, death, loss, and suffering. Still, in spite of our exorbitant efforts to delay aging and death, reality eventually sits in: sooner or later, independence will become impossible; our bodies will shut down (Gawande, 2014). We will die.

Gawande and other bold voices from the healthcare field, such as Dr. Brian Goldman, the host of the radio show and podcast *White Coat, Black Art*, provide platforms and avenues for critical reflections on the culture of medicine, an imperative need in order to change the status quo. His work holds up a much needed mirror to a profession and system so deeply entrenched in archaic ways of working that detractors rarely find a platform on which to voice their concerns and recommendations.

Gawande brings death to the forefront of our attention, earnestly encouraging his audience to talk about death at some point before we die. While it is important to talk about death, Gawande's book is limited in tactical strategies in how to actually effect this desired change.

Also, if confronting death was as simple as talking about it, then why don't we just do it?

The aim of this research is to help to change the dominant culture of death and grief by building on the ideas of changemakers in and around the fields of death and grief, and by helping to support clearer pathways to more desired, alternative, and inclusive futures. As political activist, academic, author, and former Black Panther, Angela Davis, thoughtfully states in her talk *How Does Change Happen?* "we have to absolutely refuse to attribute any type of permanency to that which is, simply because it is" (Davis, 2008).

Findings, Observations and Insights

INSIGHTS AS DESIGN PRINCIPLES FOR INCLUSIVE PRACTICES AND RITUALS FOR DEATH AND GRIEF

The participant interviews provided key insights into a larger set of considerations and principles when designing practices and rituals around death and grief. Each insight is grouped with key supporting themes and data.

1.0   Common Practices and Beautiful, Welcoming Spaces to Support Death and Grief

1.1 Shared Spaces to Grieve

"I want a space where I can go anytime I need to grieve."

All of the participants identified an inclusive shared place as something they either value and have, or would like to have to go anytime to help process grief. The lack of available public space dedicated to grief can be debilitating, especially for those with limited social support.

1.2 Rituals and Artifacts Are Necessary to Help Process Grief, And Should Be Simple And Symbolic

"My husband and I had bought our shrouds for burial so I knew where to find them."

Rituals and artifacts assist in the transition that happens after the loss of a loved one. Participants emphasized the importance of keeping these rituals and associated processes simple. They also suggested that preparation, when possible, allows for some lightening of the heavy burden of coping with death and grief.

1.3 Clear Language and Ways for Others to Acknowledge And Support Grief

"My family doesn't want to talk about his death, but sharing helps me to honour the truth of what happened."

The language used to talk about death and grief is outdated. Without a clear, shared vernacular, the interviewees believe that talking about death and grief is much harder than it should be.

1.4 We Need to Value the Time and Space Required For Grief

"In the West we're so obsessed with the now. The material. If I get this thing then I'll be ok."

"We live in a task-based life. No time or space to listen."

Current societal values of time-limited mourning, compounded with compulsive busyness, does not allow for the time people need to work through the transition of losing a loved one.

Many formal support systems have been built in and around religion and religious community, especially systems providing emotional support. In a study on religion and loneliness in later life, researchers found that involvement in religious institutions was "associated with higher levels of social integration and social support" and that "social integration and social support are associated with lower levels of loneliness" (Rote, 2013).

While many people do still turn to religion or other traditions to help them prepare for and engage with death and grief, there is a growing number of the population that do not subscribe to religion or lack a place to go when seeking support with death and grief. Given that social integration and support are built through social bonding, when groups engage in activities such as shared "rituals, liturgy, song, dance, eating, grieving, comforting" (Asma, 2019), more formal programming needs to offer other ways—outside of religion—to foster social networks. This is especially true for older adults and other groups with limited social contact.

In fact, in Canada there has been a "substantial drop in religious commitment in the Canadian public" (Pew Research Centre, 2013). In 1986, 43% of Canadian adults ages 15 and older said they attended religious services; yet by 2010, the figure for Canadian adults had fallen 16 percentage points, to 27% (Pew Research Centre, 2013) (Figure 8). Further, many places of worship are exclusive to their members and some even exclude people based on how

Religious Attendance in Canada and the U.S., 1986-2012

% who say they attend religious services at least once a month
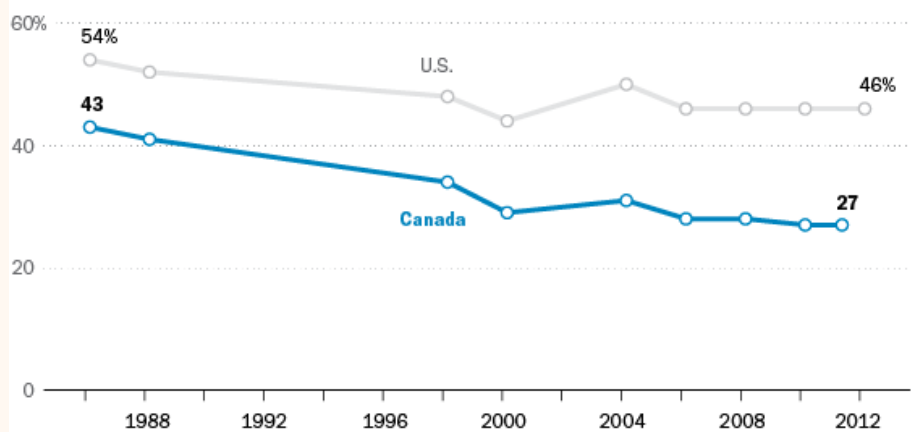
Sources: U.S. General Social Survey 1986-2012; Canadian General Social Survey 1986-2011

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Figure 8 Religious Attendance in Canada and the U.S. 1986-2012
Image source: https://www.pewforum.org/2013/06/27/canadas-changing-religious-landscape/

they may have died (e.g., suicide). The result is that many people must devise styles of mourning on their own, with limited or no social support. This lack of social support can lead to devastating effects, as the growing public health crisis of social isolation and loneliness has shown us (National Seniors Council, Government of Canada, 2016). For example, critical life transitions such as retirement, death of a spouse, and becoming a caregiver, can further increase the risk of becoming socially isolated (Keefe, 2014).

Creating a more inclusive space is what inspired David Best to build Burning Man's first temple in 2000. The temple is a solemn space that is viewed as a sacred place that can provide a sense of remembrance, grief, and renewal (Mosbaugh, 2013). In an article in the Guardian in 2016, Best is quoted as saying:

> I knew that if you're a Jew or a Catholic you couldn't be buried in a cemetery if you took your own life...When I built the temple, my intention was to make it for someone who had taken their own life. Rather than being ashamed of that, you could celebrate and honor [the person who had died]. (Thrasher, 2016).

2.0 The Presence of Others Helps to Lighten the Load

2.1 Just Listen, It's Not That Complex
"Maybe we are so stuck on what to say, on our words, because there isn't anything to say."

Participants felt that many existing interventions overcomplicate what's needed in terms of support for death and grief. Further, they identified this overcomplication in the way our current healthcare system treats patients—where everything is time-based and about referrals and deferrals. They talked about how words provide little comfort in these times.

2.2 Holding Space
"I lose a baby and there's nothing you can say to make it better. But if you just sit with me it makes all the difference."

The participants indicated that just simply having people show up and be present was helpful, and doing mundane things, such as watching a movie with them, made them know they were cared for.

In the West, the culture of "busy" can affect the way we engage with others, particularly in the way we listen. This distractedness means we may often miss what someone actually needs during a difficult time. One study conducted by Faye Doell (2003) showed that there are two different types of listening: listening to understand and listening to respond. Those who listen to understand have greater satisfaction in their interpersonal relationships. While people may think they are listening to understand, what they're often doing is just waiting to respond.

In fact, face-to-face conversations are the social glue that shapes human relationships (Turkle, 2015). When highly social animals such as humans are together, "they show a better recovery from experiences of distress," a phenomenon known as "social buffering" (Kikusui, 2006). Studies show that when social mammals have suffered separation distress, they "are restored to health by touch, collective meals and grooming" (Asma, 2019). Both individual and systemic interventions for grieving should consider these necessities.

3.0 Acknowledge That Grief is Colourful; It is Not Linear or Temporary

3.1 Grief Doesn't End, It Just Changes Form

"Time doesn't heal wounds. We grow scar tissue."

"Grief feels like you're hemorrhaging inside when no one sees your pain."

"When people talk to me about it (the death of my daughter and husband) you're not reminding me of it because I am always thinking about it."

The overall sentiment from participants was that some form of grief is always with you. You always miss the people you've lost.

3.2 The Person Grieving Often Feels Like A Burden

"Why do we care what others will think so much after a loss like this? That people will get tired of us. You worry that you will be emotionally draining for them. These were my concerns."

The burden of worrying about what others feel and think of their grief was a heavy, repeated pattern for all the participants. Were they grieving too much? For too long? These were constant worries for the participants. They described how it helped when they were assured that their grief was warranted and accepted.

3.3 Feeling Seen and Heard

"It's difficult to be emotional in a world that rejects emotions."

"If I cried I was weak and sad. If I didn't I was brave."

All of the participants talked about how hard it was to grieve because there was an expectation associated with each expression of emotion.

We need to acknowledge that grief isn't linear or temporary; it's messy, colourful and it stays with us like baggage—and sometimes people need help carrying that luggage. Acknowledgement is defined as the recognition of the existence or truth of (Dictionary.com, 2019). Without acknowledgement, those grieving often worry about how much they will burden those around them with their grief. Through regular reminders and/or check-ins from others, people who are grieving are assured that they have space to continue grieving, regardless of how they may need to process their grief.

This acknowledgement can also help a person feel better understood, which lends to enhancing their perceptions of belonging. Perceptions of belonging are essential, as "much of human behavior is driven by the need to belong and the desire to connect with others" (Morelli, 2014). Research shows that feeling understood by others can be a critical component of social connection, enhancing both personal and social well-being. Not feeling understood can lead to "increases in sensitivity to physical pain (Oishi, 2010).

Another major revelation in this research was the misunderstanding of the stages of grief. Taken from her 1969 book, *On Death and Dying*, Elisabeth Kübler-Ross developed a conceptual

Figure 9: Screenshot from Twitter
Source image: https://twitter.com/djp1974/status/1171519417328394240

framework of five stages of grief that aided the pioneers of the hospice movement. This framework also became part of modern cultural consciousness as the natural progression of emotions one experiences during grief. However, the model was not evidence-based, was not relatable to many people's experiences (Figure 9), "and was never even meant to apply to the bereaved" (McVean, 2019). It was actually intended and developed for people diagnosed with terminal illnesses.

Finally, emotions associated with grief can manifest in many different ways. Zisook & Shear (2009) note "the spectrum of emotional, cognitive, social and behavioral disruptions of grief is broad, ranging from barely noticeable alterations to profound anguish and dysfunction." Further, grief is not only about pain; it can be positive for some, yet "these positive feelings elicit negative emotions of disloyalty and guilt in the bereaved" (Zisook & Shear, 2009).

4.0 Personal Agency and Dignity

4.1 Too Much Bureaucracy in What People Want/Need Regarding Death
"My (elderly) dad wanted to die, but the hospital wouldn't let him because he wasn't dying. They said he must have a mental illness."

Participants talked about being able to know what was best for them and that their death and/or the death of a loved one should be on their terms when it's possible to plan. Two of the five interviewees talked about how their loved ones died at home and how important that was to the "letting go" process as they were present, bearing witness to the end-of-life process.

4.2 Accessibility
"We need people to talk to when we're grieving. Therapy needs to be affordable and accessible."

The participants highlighted the high cost of counseling services for grief. When they reflected on what they would like to see change, it was about removing barriers for support, such as reducing the cost of access mental health services—specifically during a terminal illness or after the death of a loved one.

Personal agency is the sense of power an individual has over actions and consequences of their own life. Being in control of one's life "means being able to do as much for oneself as possible and making one's own choices, e.g., decisions on daily matters; being responsible, to the extent possible and practical, for things that affect one; having the freedom to make decisions about how one will live one's life; enjoying access to a support system that enables freedom of choice and self-determination" (Ontario Human Rights Commission, 2001). Yet, current laws and attitudes still prohibit many people from being able to do what they may feel is best for them, particularly at the end of life. While the passing of Bill C-14, the Medical Assistance in Dying (MAID) Act in June 2016 allowed eligible Canadian adults to request medical assistance in dying, "critics have pointed out that the new legislation is more restrictive than the Supreme Court decision" (Marshall, 2016). Further, medical

professionals may not be willing to offer end-of-life services, creating further barriers. Given that "doctors are trained to save lives, not end them, and they work in a system that puts curing above caring," the medical community has more work to do when dealing with people facing end-of-life decisions.

In 2018, Sandra Martin, author of *A Good Death: Making the Most of Our Final Choices*, shared an excerpt in an opinion piece in the *Globe and Mail* highlighting these attitudes.

> The first giant step had been taken. Patients had scored a legal victory for choice at end of life. But that didn't mean doctors were willing to help them die. "Let the vets do it," an eminent practitioner told me dismissively. "Killing patients isn't medicine." (Martin, 2018)

Part of this disconnection is that universal health care is mandated under the Canada Health Act, but medical services are delivered and regulated provincially. The federal government enacted a restrictive Medical Assistance in Dying (MAID) law; provincial exemptions allow publicly funded faith-based institutions and long-term care homes (outside Quebec) to refuse to provide MAID on their premises.

According to the Ontario Human Rights Commission, dignity encompasses individual self-respect and self-worth. It involves physical and psychological integrity and empowerment. A person's dignity is harmed when he or she is marginalized, stigmatized, ignored or devalued (Moore, 2016). Audrey Parker, an advocate for dying with dignity, ended her life on November 1, 2018, with the Canadian Medical Assistance in Dying (MAID) program; in a video released by Dying with Dignity Canada, she affirmed, "People like me who have already been assessed and approved are dying earlier than necessary because of this poorly thought-out law" (Dying with Dignity Canada, 2019).

In a debate prior to the October 2019 federal election, re-elected Prime Minister Justin Trudeau said the Liberals would relax the laws around assisted dying within 6 months of being re-elected (Browne, 2019).

Self-reported health status is now one of the most common measures used in public health surveys in Canada. It represents physical, emotional, and social aspects of health and well-being. How people feel about their own health is seen as a good indication of the burden of disease. People's perceptions of their own health have been found to be a good predictor of future health-care use and of mortality rates (Conference Board of Canada, 2015). Given that, medical professionals need to listen to how people feel, and advocate for the wishes of their patients. More efforts need to be made in supporting families to respect the wishes of loved ones close to death.

5.0 The Need for Death and Grief Literacy

> **Important to Note:**
>
> - These were the most prevalent themes interviewees touched on
> - This provides a foundation that underpins the development of the other insights and principles
> - All participants shared how great it felt to have the experience of discussing the topic of death and grief.

5.1 We Don't Know How to Talk About Death

"If I say I miss my Dad someone will say 'we all do.' I want to say 'it's not about you,' I'm just sharing my grief."

"We don't talk about death because we are so positive-oriented. Some emotions are ok and some aren't, even though we know that's bullshit."

Participants pointed out how disconnected language is from the actual experience of grief. We use language that is outdated (e.g., greeting card sentiments), and/or we say things that completely ignore or avoid what the person is feeling.

5.2 Lack of Preparation and Understanding

"Teachers and guidance counsellors weren't trained to know what to do when parents die."

Death and grief are not traditionally addressed in current public education discourse.

5.3 Death is Taboo

"We mention death in casual ways, but we don't talk about it. When we do it seems morbid."

Death has become so removed from everyday language that it is no longer comfortable for people to talk about it. Discussing death is often seen as tactless, rather than a topic to openly discuss.

5.4 Public Education is Needed

"I think about who I was before and how I didn't understand why people were so sad during anniversaries. It's a deep grief."

"Stages of grief are not a real thing. You're always moving around the different stages, but grief is always there, lurking underneath. You carry it with you."

"Talking about death is a collectivist, community building discussion."

Participants talked about how even within or outside of religion there is still a gap in knowledge about how to engage with death and grief. According to Victor Marshall, a sociologist formerly at the University of Toronto Medical School and author of Last Chapters: A Sociology of Aging and Dying, "most people don't think much about death or their own mortality until they see their parents growing old," which can be problematic, leaving people filled with regret. The current understanding of death is heavily influenced by the media, specifically films and TV, which can be limiting and misguided in their scope. When children are actually educated about death, they are likely to be better prepared for, and better able to make sense of death when it does happen (Seeley, 2018).

5.5 Being Present, Mindful and Honest

"Death is a certainty. We know it will come."

"If we're suppressing negative emotions, we're also suppressing positive emotions."

"Don't place too much relevance on the events in your life. They are transitory. The journey is not about the degree, the house, it's about basic human principles."

Participants observed how our inability to accept death often comes from the many distractions we face, seemingly causing us to forget that this absolute truth for all human beings comes whether we are prepared for it or not. They noted how being honest, present and aware of death allows one to be mindful about what may actually be most important to them.

Death literacy is defined as "a set of knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options" (Noonan, 2016). While I was not able to find any definitions of grief literacy, Lynda Cheldelin Fell, co-founder of the International Grief Institute in the United States, affirms that, "grief literacy in our country remains rooted in the dark ages" (Cheldelin Fell, 2015). While it's hard to know exactly how grief was accepted and/or expressed during the dark ages, her point is taken. Our cultural understanding of grief is exceptionally limited.

People want to talk about death and grief; they just lack the tools and capabilities. While the majority of Canadians (52%) indicate that the advance care planning process should begin when a person is healthy, only 13% of Canadians have an advance care plan prepared (Canadian Hospice Palliative Care Association, 2014). Further, talking about death and grief does not have to be, and ideally should not be, only during a crisis. It can be a way to better understand people, to see their humanness. Talking about death allows us to acknowledge it, to create clarity and alignment about what may be needed during death and grief. As a design and strategy consultant myself, I have found that building alignment through dialogue is the only way to work through strategy development and/or solutions.

While religion may be able to provide some support for people in preparing for, and/or dealing with death and grief, religious practices and rituals still have gaps. They do not always provide the necessary education needed for empathy or compassion for grief. Three of the four participants had grown up with some religious affiliation, and one of them was still actively engaged in their faith. All of them shared that in spite of their religious teachings, they still felt unprepared and ill-informed about how to support others in grief.

In fact, in Canada, religion is decreasing, and secularism is increasing (Figure 10). "The number of Canadians with no religious affiliation has been rising, and attendance at religious services has been dropping" (Pew Research Centre, 2013). Further, as noted earlier in this paper, rituals concerning death have steadily been replaced by institutionalization and professionalization.

Growth of the Religiously Unaffiliated in Canada and the U.S.

% of population that identifies as religiously unaffiliated

Sources: U.S. General Social Survey 1972-2012; 1971-2001 Canada census; 2011 National Household Survey
Figures for the U.S. are for adults only (ages 18 years and older); figures for Canada include adults and children.

PEW RESEARCH CENTER
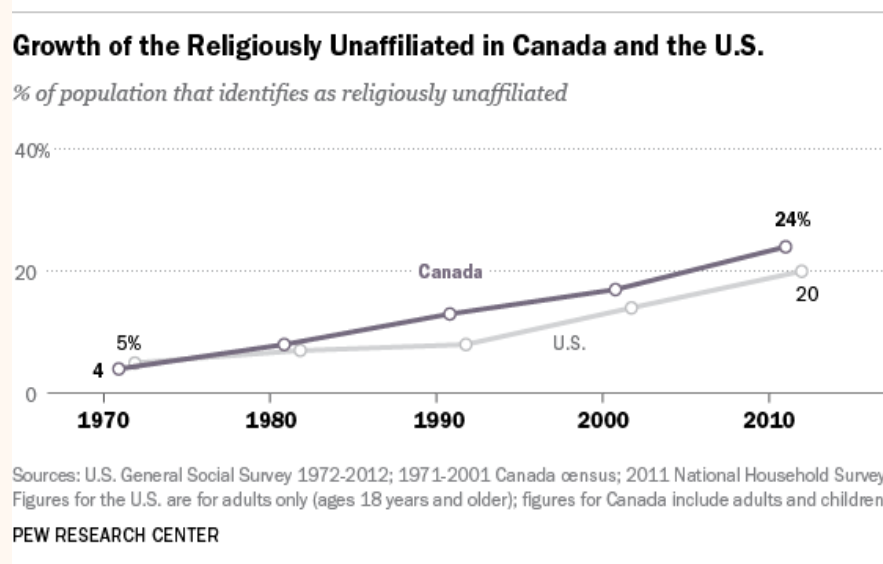
Figure 10: Growth of the Religiously Unaffiliated in Canada and the U.S.
Image source: https://www.pewforum.org/2013/06/27/canadas-changing-religious-landscape/

Workshop Design, Observations, and Insights

While my individual analysis was useful to synthesize an initial understanding of the data, a playback to workshop participants helped to add more clarity, analysis and deeper insights into understanding this cultural phenomenon. In addition, bringing diverse individuals into the analysis allowed for additional perspectives and voices to be leveraged and represented.

When asked about what spurred their interest in participating in a workshop on the topic of death and grief, participants stated reasons such as wanting "a deeper dive to understand" and being "close to death, but not directly" and wanting to be able to "just talk about it." The workshop was broken into three parts consisting of:

1. Participants sharing and exploring their own personal experiences, barriers and tensions with death and grief through an activity
2. Using the causal layered analysis (CLA) to explore and dive deeper into the myths and metaphors underpinning the Western cultural norms of death and grief practices and rituals
3. Presenting the design principles surfaced in the participant interviews to brainstorm headlines of alternative and more desired future states

PERSONAL TENSIONS

Figure 11: Workshop participant's worksheets
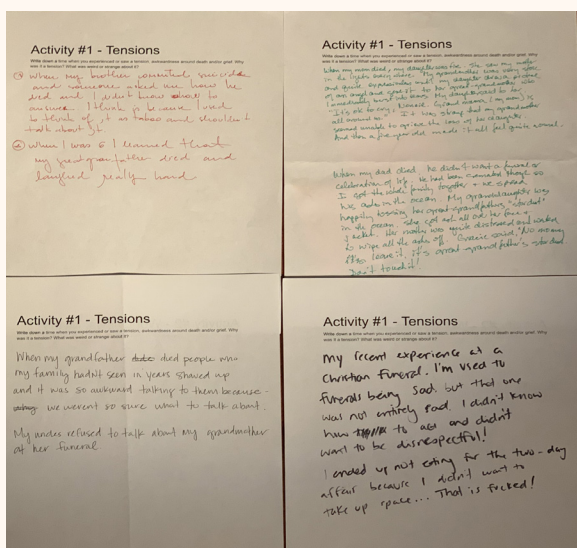
To help to validate and understand more deeply the tensions that were surfacing in the CLA, participants were invited to share personal anecdotes of tensions (Figure 11) they had personally experienced when dealing with death and grief.

EXPLORING MYTHS

The causal layered analysis was used as part of an exercise to develop alternative futures and a preferred vision for death and grief practices and rituals. This activity facilitated a generative discussion of myths and metaphors. When discussing current myths, participants discussed how current practices and rituals "disconnect us."

"Even in the practice of embalming there's this idea of not letting the person look like they died. It's so weird that we do that."

—Workshop Participant

Grief was described by one workshop participant as being "like a beach. Sometimes high tide sometimes low tide; it's ever present it doesn't always take you over."

The discussion around what the new myth might be focused on accepting death and the benefits that this shift in mindset could have on society. There was overall agreement from participants that death can create ways to connect and reconnect with others; that accepting death makes you appreciate life and that accepting mortality can help one live a better life as it requires mindfulness and presence.

The final activity moved participants from the new myth into Headlines From the Future activity of what might emerge in more desired and/or alternative futures (Figure 12). Participants shared headlines ranging from systemic interventions of death and grief literacy integrated into school curriculum, to celebrities preparing for death.
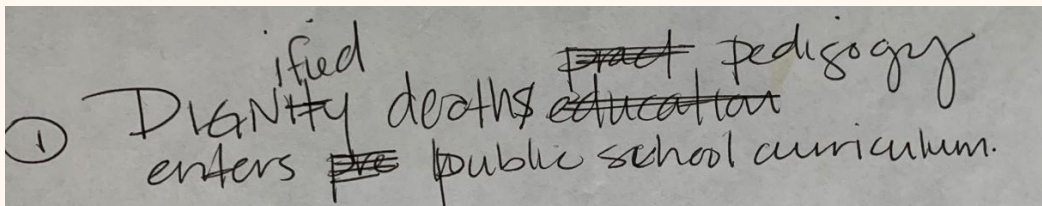
Figure 12: Workshop participant's headline from the future

Participants concluded by sharing final reflections of the process. They enjoyed using the CLA to explore such a taboo topic.

"I wish more of this happened."

—Workshop Participant

"(This format) We could step outside of our own experiences it felt cathartic. Talking about it with other people can be awkward and then there's a wall."

—Workshop Participant

"Not only are we denying death but these complex family dynamics…we don't talk about death we don't talk about dynamics so things get left unsaid…builds resentment."

—Workshop Participant

Causal Layered Analysis: Looking at the Problem Through Layers

Before designing solutions or interventions for the future we need to understand the present context. Causal Layered Analysis (CLA) emphasises the importance of understanding reality through different layers of knowing and observing things, allowing for multiple perspectives to be considered within one approach. This includes integrating different futures perspectives such as the empirical, the interpretive, the critical, and time horizons (Inayatullah, 1998). Only by understanding the deeper, more complex underpinnings of an issue is it possible for genuine change to occur, as it questions the underlying systems and social structures that proliferate the issue in the first place (Bishop et al., 2013).

As the CLA is an interpretive methodology within the field of futures research, it was applied for analysis and synthesis of data from the literature review, interviews and workshop. Since the CLA allowed for various perspectives of an issue to be included, it also helped to situate the issue within broader social structures where issues are felt and experienced. Given this, I mapped the various dimensions of the past and the present mindsets, attitudes and systems perpetuating current cultural norms around death and grief. By "deconstructing conventional metaphors" this helps to articulate "alternative metaphors," which can become "a powerful way to critique the present and create the possibility of alternative futures" —in the case of this research, focusing on death and grief practices and rituals (Inayatullah, 1998).

An initial pass of the CLA analyzed the data horizontally, within each layer, surfacing an initial set of insights. With direction from my Principal Advisor, a second, more insightful deconstruction vertically, through the layers, illuminated an interesting contrast across the CLA: patterns of subjective human needs and emotions attempting to be addressed with capitalistic, logical and rational interventions. The following diagrams showcase the progression from the CLA to the themes and tensions, leading to the unveiling of the underlying cultural myths.

Figure 13:Themes from the causal layered analysis (CLA)

This was initially identified through a series of themes (Figure 13) that were then clustered (Figure 14).

Figure 14: Clusters of the themes from the causal layered analysis (CLA)

Through the clusters, a set of tensions emerged (Figure 15), which helped to build a clearer understanding of how current Western cultural rituals are influenced. As humans we are guided by our emotions and feelings; yet since the "age of reason," as a culture, we have invested greatly in rationality, logic, and science.

Figure 15: Tensions revealed in the causal layered analysis (CLA)

	Human Experience; Humanism				Rationality; Age of Reason; Science		
	Need for Meaning	**Human Nature**	**Education**	**Cultural Rituals**	**Death Industry**	**Control / Efficiency**	**Science / Medicine**
Litany Our day-to-day, viewed through current events, social and behavioural trends.	Pop-up events, games about death Bespoke personalized funerals	Inability to cope Social isolation Desperation to be a part of something (fitting in)	Googling what to say when someone dies Mourning is an individual activity Unprepared for death	Grief is prviate Delegation of loved one's bodies to approved services	Advertisements of funeral industry Luxury coffins	We shove death away till we're old Malpractice lawsuits Social media algorithms control what is seen	Plastic surgery Medicine for elimination of pain and sensation
Systems Social structures including but not limited to economic, cultural, political and historical factors.	Academics studying death Religion Nationalism	Independence Grief therapy is expensive You are defined by what you do	Death can only be discussed in certain places and times No formal education on how to address death and grief	Post-colonization Corporatization	Cremation is fast and cheap Consumerism Capitalism Neoliberalism	Hierarchy Gender norms Binaries	Science system of knowledge Quantity of life Institutionalization of dying Big Pharma
Worldviews A more "imaginative" landscape which affects the structures we put in place and the way we understand the events.	Existential dualism (we are animals but we have conscious My life and death has purpose My legacy defines me	Only happy, positive emotions Read this book and everything will be ok	Grief is a burden Talking about death is morbid Death is taboo	Grief is temporary It takes a lot of courage to talk about death No time for grief Only funerals are for grieving	Embalming memorializes the dead Death should be taken care of by someone else The more money we spend the more we love	Evil can be eliminated with supervision and punishment We are included when we follow the roles	Death is a failure Hospitals only place for medical expertise Doctor is decider of life and death

Myths
The usually unconscious and collective archetypes, paradigms and cultural stories and images which shape the worldviews.

Death is a right of passage to a better world, if you're a good person

Death is one more disease to be conquered

Figure 16: The Causal Layered Analysis[1].
The matching shades of colour on each side of the CLA aim to help to guide the reader to the panarchy-like flow back and forth across the diagram revealing the tensions on each side.

1 A high definition of this figure is available in OCAD University Open Research Repository

This contrast further reveals two oppositional myths in Western culture. The left side of the CLA (Figure 16) reveals the myth of death as a right of passage to a better place—if you're a good person. Yet, on the right side, the myth is that death is conquerable. This dichotomy of the emotional versus the rational is a tale as old as the Greek gods Achilles, Hercules, Demeter and Apollo on the left (perfection impulse), and Prometheus and Daedalus on the right (attempt to triumph over nature).

CAUSAL LAYERED ANALYSIS TO DEEPEN UNDERSTANDING OF THE PROBLEM

This final step in conducting a CLA "requires the researcher to consider the overall message or finding from the analysis in relation to the research question" (Bishop et al., 2013). This helps in guiding the proposal to alternative, more desired futures, as well as considering "strategies proposed for its resolution" (Bishop et al., 2013). As noted, the current myths are not serving many people for the future they want, therefore changing the myth(s) can lead to changing human experiences, influencing cultural rituals. In the case of this research, a new myth was derived from all the data collected.

In order to challenge the current future, we need new metrics to change how we measure the future (Inayatullah & Milojević, 2004). In regards to dealing with death and grief culturally, a first step toward acknowledgment is accepting death and grief as a natural part of life (Figure 17).

Figure 17: Fallen Trees over rainforest creek
Image Source: Justin Mckinney

INSIGHTS AND OBSERVATIONS FROM THE
CURRENT STATE CAUSAL LAYERED ANALYSIS

The analysis below helps to define and break down the key sections and insights from the Causal Layered Analysis.

	Definition	Insights or Observations
Cultural Rituals	Actions that express shared meanings. Create familiarity which help us deal with change(s), such as grief.	Current Western cultural death and grief rituals have been largely redefined and modified by private industry. We have been presented with very particular images regarding death and grief in our culture—funeral services, cremation, and embalming. Lack of death education and exposure to death leaves many people uncertain of what to do when they lose a loved one. There are cultural expectations about what grief is and how it should be experienced.
Death Care Industry	The many establishments that provide a wide range of death and grief products and services.	The death care industry is the only place that provides death information and "education." It has presented its offerings as "universal in need but individual in application" (Sanders, 2009). The death care industry manipulates our human needs to fill the gap of meaning making.
Education	The act or process of imparting or acquiring general knowledge, developing the powers of reasoning and judgment, and generally of preparing oneself or others intellectually for mature life. "The one continuing purpose of education, since ancient times, has been to bring people to as full realization as possible of what it is to be a human being" (Foshay, 1991).	Religion offers some, but still limited, guidance regarding death and grief There is a general cultural assumption that only designated professionals can engage with the topic of death and grief. Lack of formalized public education about death means we don't have a common cultural vernacular to discuss death, which creates discomfort when having to deal with death and grief. This gap has prompted the development of pop-up events like death cafés, and the creation of death board games to try to help people develop a better understanding of death and grief.

Human Nature	The qualities common to humanity. The psychological and social qualities that characterize humankind, especially in contrast with other living things.	Death is an important milestone that we as humans need to acknowledge. "No culture has been indifferent to mortal remains. Even in our supposedly disenchanted scientific age, the dead body still matters—for individuals, communities, and nations...We live with the dead because we, as a species, live with the dead" (Laqueur, 2015). Social behaviour is affected by control and efficiency.
Seeking Meaning	What we do to have relevance in the world. While humans share with all life-forms a biological predisposition toward self-preservation in the service of reproduction, we are unique in our capacity for symbolic thought, which fosters self-awareness and the ability to reflect on the past and ponder the future. This spawns the realization that death is inevitable and can occur at any time for reasons that cannot be anticipated or controlled.	Meaning making is defined by industry and reinforced through government policies. Terror Management Theory (TMT) posits that when people are reminded of their mortality, they may increase "investment in the social and cultural identities that provide meaning and perceptions of death-transcendence" (Greenberg, Pyszczynski, & Solomon, 1986). The awareness of death engenders potentially debilitating terror that is "managed" by the development and maintenance of cultural worldviews. We endeavour to be part of something that transcends biological existence. Dead bodies matter because humans have decided that they matter, and they've continued to matter over time even as the ways people care for bodies have changed. Duality of having self-awareness and being an animal that lives, dies, decays as all other animals do makes it hard to understand the purpose of life.
Power through control and efficiency	Power gives people the ability to control themselves and their environment, and this control is considered a fundamental human need (Yang, 2015).	The state controls the disposition of corpses. Being buried without a name (anonymously) has become culturally disturbing. "The corpse (or cadavre: cadere, to fall), seen without God and outside of science, is the utmost of abjection. It is death infecting life. . ... As in true theater without makeup or masks, refuse and corpses show me what I permanently thrust aside in order to live. There, I am at the border of my condition as a living being." (Kristeva, 1984).

Science / Medicine	A branch of knowledge or study dealing with a body of facts or truths systematically arranged and showing the operation of general laws ("Definition of science [Def. 1]," n.d.)	Doctors are trained to save lives, not end them, and they work in a system that puts curing above caring (Martin, 2018).

Looking at the Problem Through Systems

"Today's problems come from yesterday's solutions."
—Peter Senge, 1990

Systems are comprised of structures, processes, and outcomes; system maps help to show the connections in a system and how things unfold over time. They also help clarify or dispel assumptions and look at the whole context of a particular problem or issue. They are useful for gaining insight into the nature of the underlying problem and for offering a basic structure or foundation for understanding.

System archetypes help to describe common patterns of behaviour within a system, making time an explicit variable. In systems "certain patterns of structure recur again and again" (Senge, 1994), driving the need for effective tools to answer the question, "why do we keep seeing the same problems recur over time?" (Braun, 2002).

SYSTEM ARCHETYPES TO SYSTEM INTERVENTIONS

"The purpose of the systems archetypes is to recondition our perceptions, so as to be more able to see structures at play, and to see the leverage in those structures"
—Peter Senge, 1994

The tensions highlighted in the CLA informed the development of a series of system map archetypes. These visual representations help to show how system components are interacting and influencing each other. This process is helpful to articulate and identify intervention points in this system to create more inclusive options to prepare for death and grief.

Limits to Growth Archetype

Figure 18: Limits to Growth system archetype
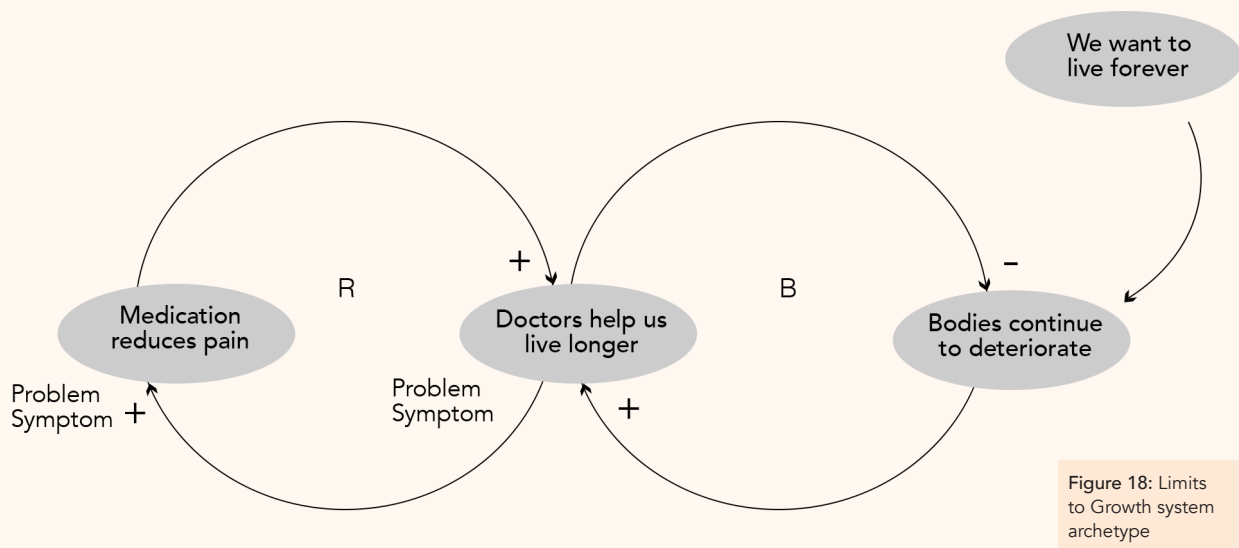
Growth cannot continue unabated in an unrestricted reinforcing dynamic (Braun, 2002). In the current system science and doctors help us live longer lives through the administration and control of medicine for elimination of pain; this is a reinforcing loop. Yet the fact of the matter is that our bodies deteriorate as we age. Medicine can help to eliminate or minimize pain but eventually medicine won't be able to save us. Our bodies have limits. Further, as noted in the causal layered analysis, death is seen as failure; thus, doctors then bear the burden of that failure. Advancements in medicine often feel hopeful, that we will survive another disease, live a few years longer, but to what end is all of this for. "What do we want to want?" (Harari, 2016).

While medicine can help to eliminate disease and prolong life, it diverts attention away from the fact that there still exists a cultural denial of death. This is demonstrated in our lack of preparation for death. For many, when the death of a loved one is close, feelings of regret can start to emerge for not saying or doing things they wish they had done, and/or having to make critical decisions in a vulnerable state.

If we don't plan for limits, we are planning for failure.

Fixes that Fail

Figure 19: Fixes that Fail system archetype
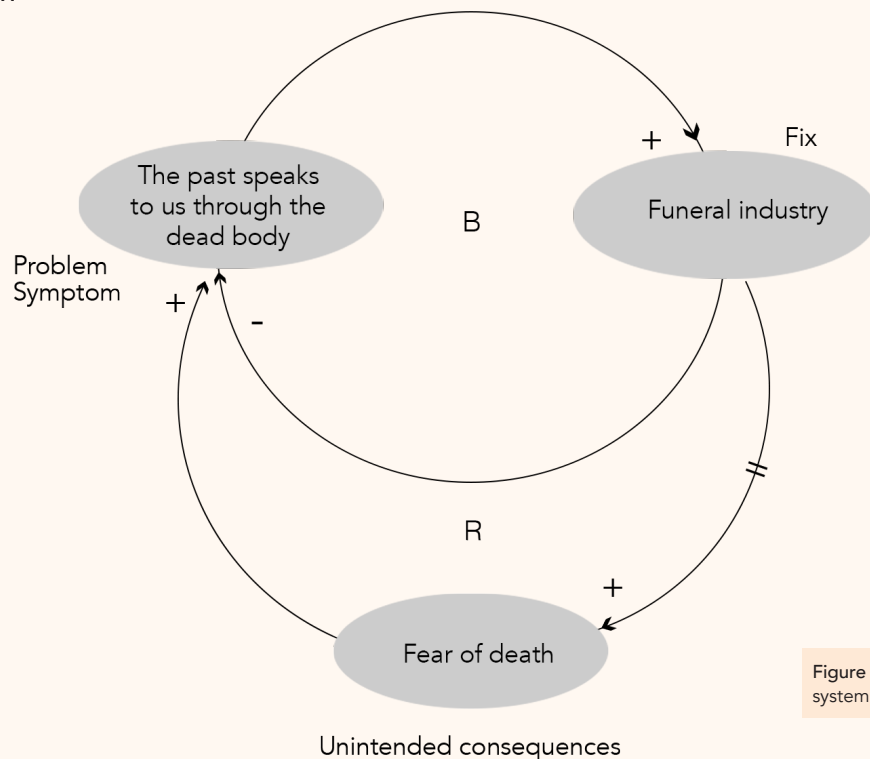
In fixes that fail, a fix in the short term creates side effects for longer-term behaviour. Our inability to prepare for death or engage with the topic of death makes it very hard to cope when someone dies. In the current system, the dead body has great power to influence decisions. Whenever a death occurs, many people are misinformed and/or unprepared, and turn to the funeral industry to provide guidance to support, and most importantly honor, this tragedy. For many people, the death of a loved one has only been considered and/or discussed during heightened states of vulnerability. The sheer unpreparedness and discomfort with death is how the funeral industry thrives, capitalizing on vulnerable buyers through a transaction that takes care of everything regarding death, completely absolving the family of the burden of the dead body. But funerals don't relieve our anxiety about death and grief.

We never deal with death, and so our fear never gets resolved.

From Shifting the Burden to Sharing the Burden

"The shifting the burden structure, if not interrupted, generates forces that are all-too-familiar in contemporary society. These are the dynamics of avoidance, the result of which is increasing dependency, and ultimately addiction."

—Peter Senge, 1994
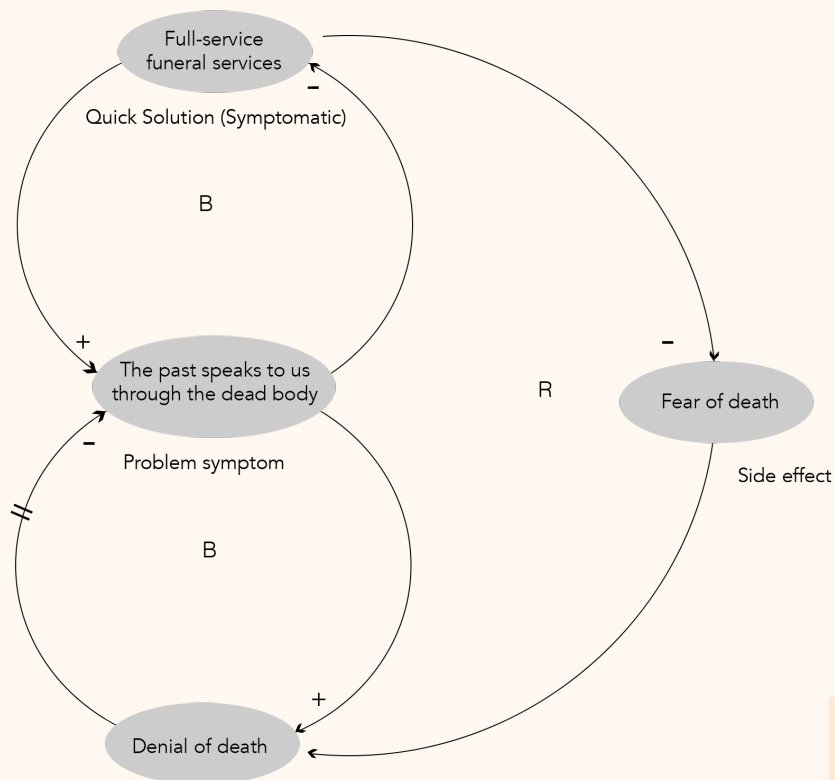
Figure 20: Shifting the Burden system archetype

The shifting the burden archetype explains why well-intended "solutions" can actually make matters worse over the long term. Opting for "symptomatic solutions" can be enticing because of the quick fix. And while symptomatic solutions are sometimes necessary, "they must always be acknowledged as such, and combined with strategies for rehabilitating the capacity for fundamental solution, if the shifting the burden dynamic is to be interrupted" (Senge, 1994).

In most shifting the burden structures, there are two possible areas of leverage: (1) weaken the symptomatic solution and (2) strengthen the fundamental solution. One way of weakening the symptomatic solution is diminishing the emotional threat that prompts the defensive response in the first place. (Senge, 1994).

In this case, as mentioned previously, the funeral industry provides helpful and useful services, but there is never truly an alleviation of the problem: how we deal with death. In the case of death and grief in Western culture, it is not about removing the funeral industry, but about creating ways to incorporate the new myth of death as natural part of life as birth, to deal with many of the issues face today.
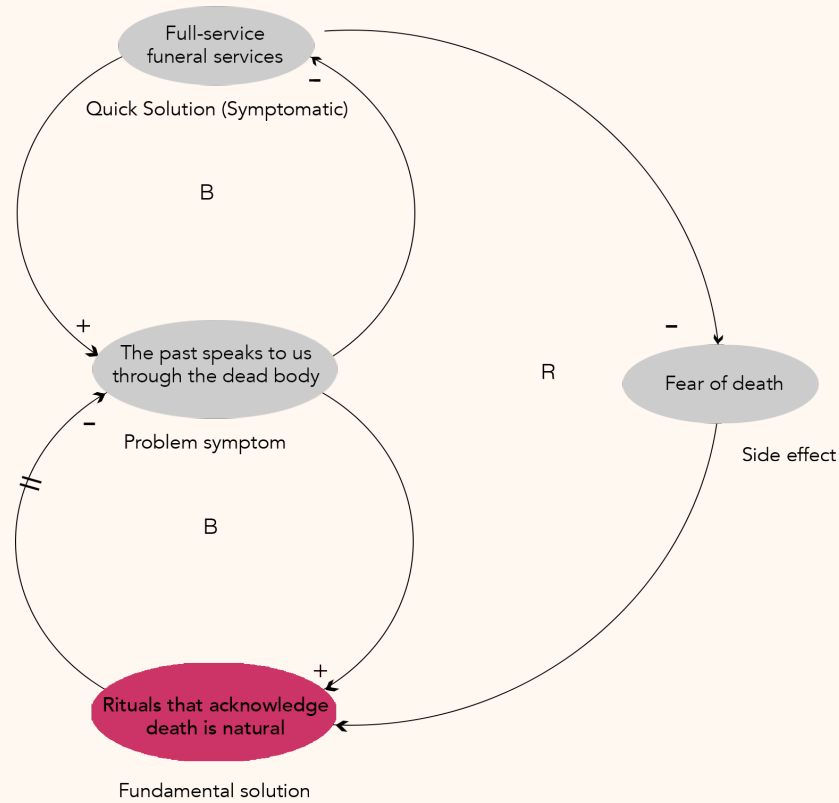
Figure 21:*Sharing the burden* system archeytype

Incorporating a more human-centred approach to the shifting the burden archetype could lead to more of a *sharing the burden* archetype to help achieve the desired new myth—to create rituals to help us acknowledge that death is natural and that grief requires time, community and love to process, and that grief is in fact not temporary.

Revisiting the Research Question

How have social practices preparing for death and grief evolved in modernism and what design opportunities emerge to transform these practices?

Sub-Questions:

- How might we use end user experience to guide the principles of design?
- How might the design process and methods help to identify system intervention points to create more inclusive ways to engage with death and grief?

My initial interest in pursuing this research was to better understand how we evolved to current cultural practices around death and grief, and to better understand where there may be design opportunities. Through looking back I uncovered numerous influencing factors that led to current cultural norms.

ESTABLISHING A FOCUS FOR GENERATING ALTERNATIVE, MORE DESIRED FUTURES

While modernism has eroded much of the social cohesion and emotional meaning in death and grief rituals, the opportunity to design new and/or alternative ways for the fulfillment of human experience is ripe to prepare for death and grief. A reframing of the original research question helps to focus on design interventions.

How might the design process and methods help to identify points of intervention within the system to create more inclusive ways to engage with death and grief?

Designing for the Future

"As we move into a more eternal, longer life, death moves further and further away from us…"

—*Susan Sontag, Illness as Metaphor, 1975*

Using a design thinking process, the goal of this research has been to explore current understanding and uncertainties about death and grief rituals in Western culture, and to discover and identify opportunities to design more inclusive Western death and grief practices and rituals. The learnings have revealed intervention opportunities to address and/or challenge current cultural norms around death and grief.

By engaging people with lived experiences this helped to identify opportunities to create more inclusive Western cultural death and grief practices and rituals. Insights and design principles have manifested to be considered for future interventions.

As a final phase for this project, a speculative design approach is taken to demonstrate the possibilities for change. In the sections that follow, I present a speculative prototype of what could be. It should be emphasized that the speculative design presented is not meant to look like a finished or refined product—simply a conceptual approach to push boundaries and challenge deeply embedded values, biases and assumptions, and to illustrate alternative more desired futures.

SPECULATIVE PROTOTYPES

"I guess the way you change the future is to change people's narrative. Change the story people have imagined the future will be. Change that and you change the future. Everything else is far too complicated and out of a single person's control—but just change the story we tell ourselves about the future and you change the future itself."

— *Cory Doctorow, 2011*

Inayatullah (2004) states that:

> …who generally solves the problem/issue, also changes at each level. At the litany level, it is usually others—the government or corporations. At the social level, it is often some partnership between different groups. At the worldview level, it is people or voluntary organisations, and at the myth/metaphor it is leaders or artists. (Inayatullah & Milojević, 2004).

Working within a speculative design approach means to consider design's important role in the study of society and its future. According to Italian speculative artist/designer Fara Peluso, "being speculative means being critical about the contemporary condition, asking what future we want and who we want to become as people in relation to nature and new technologies." She calls speculative design "a great learning tool which analyses and studies our society" ("SpeculativeEdu | Interview: Fara Peluso," 2019).

For the purpose of this research, speculative design is used to contribute to creating more awareness about death and grief practices and rituals, providing ways to generate discussion about plausible artifacts from the future. The artifact is aimed at challenging assumptions and givens about the role that products play in everyday life as well as presenting new ones that may be at odds with those of today (Dunne & Raby, 2013). Through the design of critical objects and speculative narratives, the speculative artifact spurs social debate on what is a preferable development (Malpass, 2017).

This materialization of the speculative aims to enhance our ability to work with possibilities, and to reflect on how we might make better decisions in the present by having a more complete sense of alternative futures. By enabling the communication and exchange of speculative ideas and provocations of plausible, alternative futures, this can help to disrupt cultural norms—providing new design concepts that embody ideas about alternative ways that the world could be. It is about how to get more people more deeply engaged in thinking about their futures and the role of their own agency in shaping them. In this case, the focus is on how we engage with death and grief in Western culture.

SPECULATIVE PROTOTYPE: CANADA'S DEATH AND GRIEF GUIDE

"Desmond Tutu once remarked that 'we cannot be human alone; we can only be human together.' A corollary of that might be that we cannot be educated alone; we can only be educated together."

—Alan T. Wood, 2009

What if the government of Canada created a well-being death and grief guide to begin a national conversation about death?
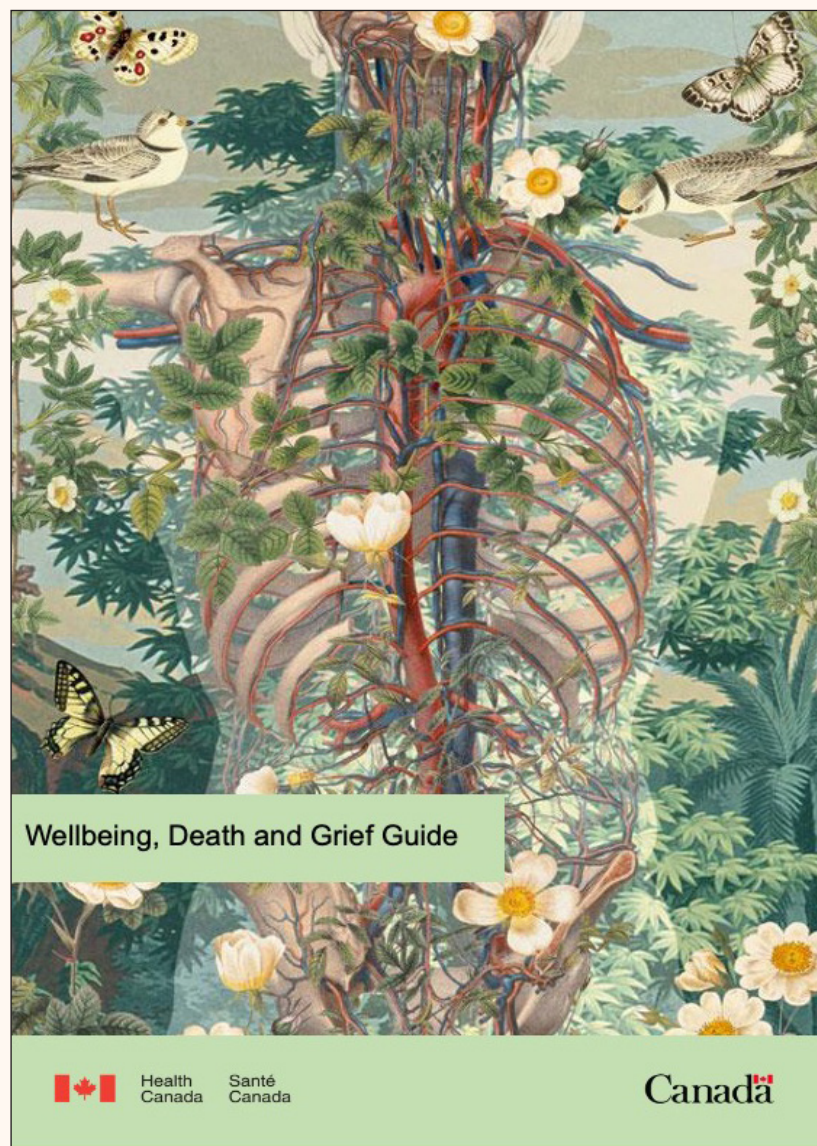
Figure 22: Prototype of speculative prototype
Graphic Source: https://www.designboom.com/art/juan-gatti-the-natural-sciences/

"The transition from the calm and monotonous world of everyday reality to the inner world of the feelings is not made spontaneously or without help. The distance between languages is too great. In order to establish communication it is necessary to have an accepted code of behaviour, a ritual that is learned by experience from childhood."

— Phillippe Ariès, 1981

Now imagine…the year is 2029.

Health Canada is slated to release The Canadian Well-being, Death and Grief Guide in January 2030 as a supplementary material part of the Canada Well-being Program—which, according to Health Canada, is billed as a long-term and comprehensive approach to "help everyone in Canada toward the well-being that comes from talking about death and grief."

The Health Canada website states that "death and grief guides are basic education tools that are designed to help people better engage." Grief can have damaging effects on a person's overall well-being and can lead to a variety of "physical and emotional issues, such as depression, trouble sleeping, feelings of anger and bitterness, anxiety, loss of appetite, and general aches and pains" (Harvard Medical School, 2018).

A preliminary table of contents has been generated based on the first round of consultations. A second series of consultations will begin to take place to further develop the content in the coming months. To find out how to participate please contact Health Canada.

Wellbeing, Death and Grief Guide

Health Canada Santé Canada

Canada

Overview

Why Talk About Wellbeing, Death and Grief?
Death Literacy
Grief Literacy

Common Practices and Beautiful, Welcoming Spaces to Support Death and Grief
Shared Language and Ways to Support Grief
Shared Spaces to Grieve
Simple and Symbolic Rituals and Artifacts

Understanding Grief
Time and Space Needed for Grief
Supporting Others in grief

Holding Space
The presence of Others Lightens the Load
Suggestions For Friends And Family Members
Conversations to Have With Loved Ones

Making Arrangements
Key Information to Help you Plan in Advance
Celebrations of Life
Burial Options

Figure 23: Protoype of table of contents of speculative prototype

The program contains other supplementary materials such as six lesson plans for teachers called "Let's Talk About Life and Death," and a card game on the topic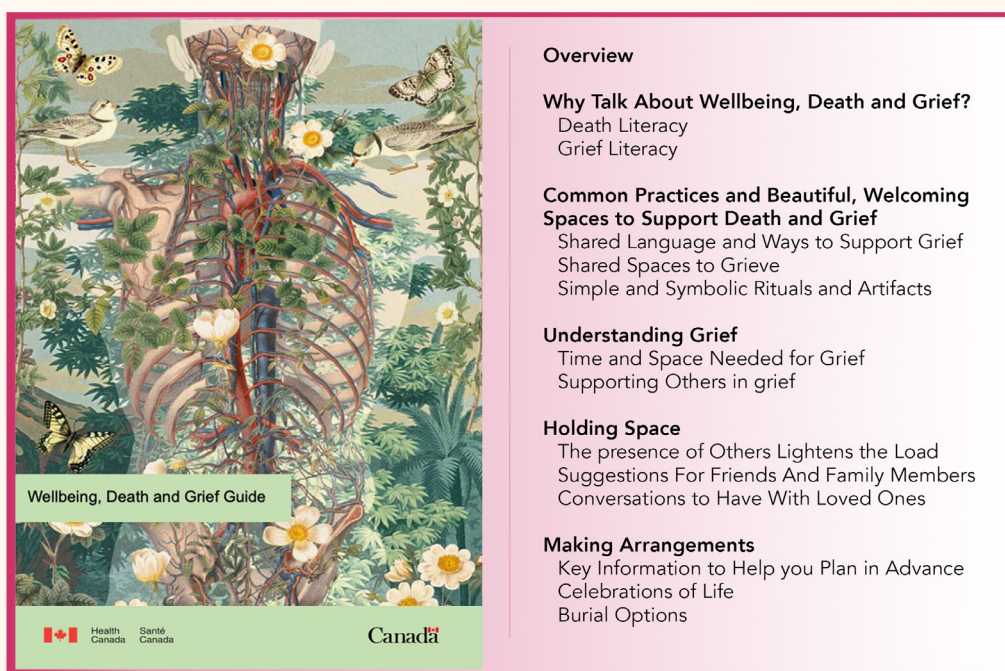 of death and grief, which can be downloaded from the Government of Canada's website. In addition, a series of posters, produced under the title "How to Prepare for Death and Grief," are available for download or can be delivered by drone via Canada Post. Materials are available in French, English Cree, Inuktitut, and Ojibwa.

WINDTUNNELING THROUGH THE CLA: WHAT DOES IT AFFECT?

Placing the speculative prototype at the systems level on the Causal Layered Analysis we can begin to see where and how this type of intervention may have the most impact.

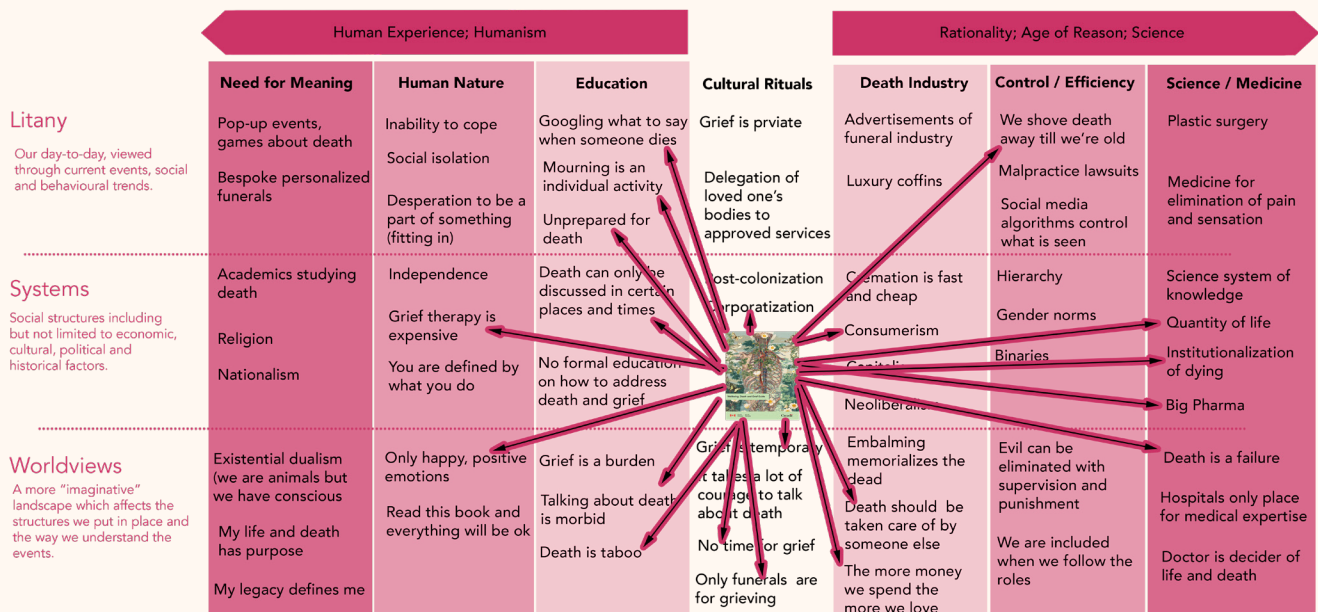|	Human Experience; Humanism				Rationality; Age of Reason; Science		
	Need for Meaning	**Human Nature**	**Education**	**Cultural Rituals**	**Death Industry**	**Control / Efficiency**	**Science / Medicine**
Litany — Our day-to-day, viewed through current events, social and behavioural trends.	Pop-up events, games about death; Bespoke personalized funerals	Inability to cope; Social isolation; Desperation to be a part of something (fitting in)	Googling what to say when someone dies; Mourning is an individual activity; Unprepared for death	Grief is prviate; Delegation of loved one's bodies to approved services	Advertisements of funeral industry; Luxury coffins	We shove death away till we're old; Malpractice lawsuits; Social media algorithms control what is seen	Plastic surgery; Medicine for elimination of pain and sensation
Systems — Social structures including but not limited to economic, cultural, political and historical factors.	Academics studying death; Religion; Nationalism	Independence; Grief therapy is expensive; You are defined by what you do	Death can only be discussed in certain places and times; No formal education on how to address death and grief	Post-colonization; Corporatization	Cremation is fast and cheap; Consumerism; Capitali...; Neoliberal...	Hierarchy; Gender norms; Binaries	Science system of knowledge; Quantity of life; Institutionalization of dying; Big Pharma
Worldviews — A more "imaginative" landscape which affects the structures we put in place and the way we understand the events.	Existential dualism (we are animals but we have conscious; My life and death has purpose; My legacy defines me	Only happy, positive emotions; Read this book and everything will be ok	Grief is a burden; Talking about death is morbid; Death is taboo	Grief is temporary; It takes a lot of courage to talk about death; No time for grief; Only funerals are for grieving	Embalming memorializes the dead; Death should be taken care of by someone else; The more money we spend the more we love	Evil can be eliminated with supervision and punishment; We are included when we follow the roles	Death is a failure; Hospitals only place for medical expertise; Doctor is decider of life and death

Figure 24: Visual example of wind-tunneling the intervention through the Causal Layered Analysis (CLA)

Next Steps

This innovation is the first prototype in a process that requires a number of iterations. Given that this research aims to explore new ways to engage with death and grief, specifically challenging the status quo on current cultural norms, it will require time to further develop and share it with a broader audience. I plan to further develop the speculative prototype into an artifact and to present it alongside the research at future workshops, conferences, and in community—to both provoke discussion, and to continue to iterate and refine the model.

Using the insights and design principles developed, I also plan to continue to develop the other ideas highlighted in the headlines below, to explore and identify other trajectories and layers within the system of this innovation—or a future manifestation of it.

This research is the first part of a larger project with a longer-term ambition to build on existing work addressing death and grief in Canada, to encourage broader discussion of this delicate yet powerful topic.

Headline:

National Day of Letting Go: A day to talk about death, grief and loss

A time of the year dedicated to letting go. It's different than Christmas or New Years because it's not commercialized. Following inspiration from other community events such a. 100 in a day; Jane's Walks, Family Day and Mexico's Day of the Dead.

Headline:

City of Toronto opens first public sanctuary for Grief and Well-being

The sanctuary is open every day. It has no religious affiliation. Space to Share and Hold Space for Grief and Well-being.

Conclusion

"Even if the structural change that we wanted did not occur, even if relief was not brought to subjugated communities in the way we wanted, what we did manage to do was to change the terrain of the struggle"
—Angela Davis, 2007

We don't know how to talk about death because we don't talk about death.

We don't know how to talk about grief because we don't talk about grief.

In this research, I used a human-centered design approach to explore modern understandings and uncertainties about death and grief practices and rituals in Western culture. I explored academic and grey literature, spoke to a diverse set of experts in the field, and interviewed participants who had experienced the loss of a foundational person in their life. To address the challenges raised by interviewees, a series of insights and principles surfaced to be considered in future, more inclusive design to support death and grief practices in Western culture. Finally, a first iteration of a speculative prototype to showcase alternative, more desired futures was developed.

When I initially started this research, I was apprehensive about diving into what is considered such a heavy and emotional topic. What was unexpected was how easy the conversations were. All of the participants expressed gratitude for being able to share and talk about death and engage in this topic.

This research revealed that this is an opportune time to look at ways to bring discussions of death and grief to broader audiences and how important it is to look at how we can have more open and public discussions about death and grief. One speculative prototype was developed to demonstrate a more desired, alternative future. With more time I would have incorporated the additional ideas for prototypes into artifacts and I would have created immersive scenarios to provoke audiences with the artifacts using Ethnographic Experiential Futures.

Finally, I might have undertaken the research differently had I known that the topic of death and grief was more approachable, digestible, and accessible. It is only through this research that I have learned that this is a topic worth pursuing more deeply, diving in to uncover what many of us are yearning for—more accessible ways to talk about death and grief.

Recommendations for Further Action and Research

Death and grief are complex and unfold in innumerable ways for people. This research focuses on death and grief in a Western cultural context, specifically that of Canada. Given the limited number of interviews in this study, it can be argued that the results are merely directional. Future investigations of the topic of death and grief could engage a broader cohort of participants.

For Medical Programs and Institutions
A revisit to curriculum on end-of-life care can help to support a more patient-centred approach to health care. Further, use the inherent wisdom of people with lived experience to guide design interventions.

For Policy Makers
Consider how religion has shifted in our modern culture and identify levers to fill gaps, specifically reagarding death and grief. There is a need to evaluate the state's role in supporting death and grief.

For Citizens
Systemic changes can take time, and it is up to us to signal the changes we want in our culture. Find ways to create shared spaces for both laughter and grief with friends. Have conversations in advance so everyone involved is prepared, informed, and empowered before a crisis occurs. Create ways to talk about death with friends and family. There are games, booklets, and other activities to address this emotionally weighty topic with a light and loving tone.

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