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Death Management: A cultural exploration in contemporary Canada

By Christina Doyle

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About the Researcher

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Foreword

I have often thought about how I might like to be remembered when my life concludes. What will my tombstone read? What will my loved ones say in my eulogy? Will I have lived a long and meaningful life and have left a legacy that will resound through generations? Or will it be tragically cut short.

When I was a teenager, I used to wake up in the middle of the night in cold sweats, worrying and fearing that life would result in death at some point. The anxiety, as I can now recognize it to be, would strike when I was in my most lonesome time of day and could not call on anyone to ease it. But why was my subconscious so preoccupied with terror around death, when it is an unavoidable part of life?

In exploring this topic as a focus of my graduate research, I could not have known that death could be friendly – in the sense of having a circle of people who were connected to it, and experiencing healthy relationships with it. I have been fortunate throughout this journey to realize that we are at a tipping point in terms of approachable dialogue arounda part of the natural human life that remains a mystery.

The contributors in this report are inspiring and open individuals who donated their time to share their knowledge and experience on a topic that, for a large majority, remains taboo and fearsome. The various perspectives and inputs of knowledge and wisdom that form this explorative report are all actors of change. This change is occurring in the way we open up about our fears, how we work toward a better state and in the desire to live great lives that includes an understanding and acceptance of our end-of-life.

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Abstract

We are at a unique tipping point in our connection to and understanding of death and dying in contemporary Canada. This research exploration shines a light on the shifting ground of the culture of death and dying in Canada, including innovative services and the demographic context that are shifting our collective perspective. By reviewing past anthropological, sociological, philosophical, and psychological practices, the story of our modern 'fear of death' surfaces. Interviews with experts from a variety of domains within death management make known barriers, changes and innovations currently underway. Through use of the foresight model of causal layered analysis, deeply seeded cultural myths of repression and phobia are assessed in connection to the litany of current trends in death management. Application of the three horizons technique reveals a tangible vision of what radical shifts might occur in 10 to 20 years and provides a provocative awareness of how death might be perceived and handled differently in the future.

Keywords: death, dying, culture, innovation, future, foresight, Canada

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Contribution

The significance of the project and its timely research provides an understanding of the changing landscape of death and dying in Canada. We are at a unique point in our historical development and understanding of life and death, entering a new era of exploring how Canadians might navigate their end-of-life experiences and service options. The research provides perspective on the contemporary views of dying in Canada and offers insight into the incredible tension that exists in our cultural values associated with death. By examining historical events and a variety of frameworks and theories, it becomes clear why contemporary culture feels and behaves the way it does about death. The result of this research offers a consciousness about our current view ofdeath phobia and provides a framework for considering how our future collective relationship with death might experience significant or even dramatic changes. Evaluating the key forces behind the current transition of our cultural values related to death demonstrates that the death we know today might not be the death we know tomorrow. Further research could build on current changes and impacts of religious affiliation and operations within the healthcare system.



Chapter One Context & Background

"No one wants to die. Even people who want to go to heaven don't want to die to get there. And yet death is the destination we all share. No one has ever escaped it. And that is as it should be, because Death is very likely the single best invention of Life. It is Life's change agent. It clears out the old to make way for the new."

- Steve Jobs

Context & Background

WE ARE CURRENTLY UNDERGOING A TRANSITION OF OUR SHARED CANADIAN cultural perspective and repressed values of death. Our entrenched collective ideas about dying and the routine way of handling the end-of-life are becoming fractured and challenged. How might the culture of death management change over the next 10-20 years in Canada? Death is a fundamental part of our culture. We all die and through our lifespan we know others who die. Expression of death is more fundamental to our culture than we can currently reflect upon, as there appears to be a comfortable repression of death. If this repression was challenged, what meaning might be revealed? There are tangible tensions growing in our quest to prolong life and escape death through medical and technological interventions, and yet our preference remains to avoid discussing death altogether. We seem to have consciously created and continue to support a system that institutionalizes most of our dying people, hiding them away in hospitals, and yet we teach our young children about all other life

stages, including conception and birth. It would appear that Canadian culture seeks to maintain traditional burial practices, which are notably becoming increasingly unsustainable because of urbanization and concerns about the environment. These fractured lines reveal a possibly radical diversion from the contemporary cultural practices and services provided in death management. In the midst of these contradictions we have started down the path to embracing physician-assisted death. In fact, mainstream media has already published many articles about the issue and the government is leading discussions toward implementing policy in 2016. This is a key signal that we are ready to consider death and our system's ability to shift the notion of care and treatment to include death. With the advent of discussion about and feasible solutions toward prolonging life and 'solving' ageing, leaders such as Google's Calico are searching for the fountain of youth in order to buy additional time and delay the inevitable final closing of one's human life. The curious attraction to electing death at a time far beyond

our current lifespan, at a moment of your choice rather than being beholden to mother nature has captured attention around the world (Corbyn, 2015). Through this exploration and many other science and technological based life prolonging endeavours, Canadian culture is reinforcing our western tradition of fear and anxiety toward death. Despite the fact that death is inescapable, we as a society have developed deeply seeded fears about the end-of-life that are being reinforced by each generation. As Elisabeth Kübler-Ross, a Swiss-American psychiatrist and pioneer in death studies noted,

"Dying is an integral part of life, as natural and predictable as being born. But whereas birth is cause for celebration, death has become a dreaded and unspeakable issue to be avoided by every means possible in our modern society. Perhaps it is that in spite of all our technological advances. We may be able to delay it, but we cannot escape it." (Kübler-Ross, 1975, pg. 5).

Although we must inevitably die, we seem to be culturally hung up on the utter lack of control that humans have toward the natural conclusion of life. Kübler-Ross further developed a model of grief that is widely recognized today as means to understand the process of death and dying. The *five stages*

of dying (Figure 1) were developed by Kübler-Ross to provide a working understanding of the phases in which a dying person travels through at the end-of-life. Commencing with the shock of becoming aware of a fatal illness, moving into denial, followed by anger, to bargaining and lastly acceptance of one's fate, an individuals' perceptions change. As Professor Allan Kellehear wrote in the 40th anniversary edition foreword of Kübler-Ross' work, the model "encourages ordinary men, women and children to converse with their dying" (Kellehear, 2009). However, our common repression of death has resulted in the loss of the ability to understand the process. This opens the need to "forcefully widen that engagement to include a dialogue with the scientific, academic and clinical elites responsible for modern day caring of the dying... remembering that these intervene at the most sensitive and vulnerable time of our lives" (Kellehear, 2009). Today, more than 40 years after Kübler-Ross was published, these conversations remain in the very early stages. We are collectively culturally stunted in this modern time, remaining in the 'Denial' stage of death. Avoiding discussion and acknowledgement of the inevitable end-of-life allows us to feel in control of our being alive. But what is

this control-centred perspective rooted in? Ernest Becker, a Jewish-American anthropologist cast an interesting and insightful psychological perspective in his Pulitzer Prize winning novel *The Denial of Death* (1973). Becker's writing shares provocative insights of our tendency to keep the fear of death in the unconscious, in order to avoid any terror that we associate with it. Antal Polony describes Becker's perspective as the drive to avoid death in our life is the ultimate subconscious motivation to create culture and value in life.

"We are aware of the constant threats all around us, of our fragility and our tiny little place in this huge and scary cosmos. We spend much of the rest of our lives attempting to define ourselves against this reality, and it is this very drive that leads us to do pretty much everything that we do. Becker calls it our drive to 'heroics' — to build a family, to create art, to find success within society, to leave a legacy larger than we were. In essence, to live a human life as our culture knows it." (Polony, 2012).

This human condition, Becker believes, powers many of our human actions and drives our life dedication to preserving our own righteousness and success.

Building on Becker's work, the Terror Management Theory was created in 1986 by social psychologists Jeff Greenberg, Tom Pyszczynski, and Sheldon Solomon (Ernest Becker Foundation, n.d.). The theory is one that can be applied to understand our current Western view of death; otherwise referred to as the death phobia we are experiencing. Our quest to build families and fortunes and leave a legacy that is larger than us has ultimately worked against our ability to accept death as part of the cycle of life.

"The awareness of death engenders potentially debilitating terror that is "managed" by the development and maintenance of cultural worldviews: humanly constructed beliefs about reality shared by individuals that minimize existential dread by conferring meaning and value. All cultures provide a sense that life is meaningful by offering an account of the origin of the universe, prescriptions for appropriate behaviour, and assurance of immortality for those who behave in accordance with cultural dictates." (Ernest Becker Foundation, n.d.).

In contemporary Canada we enjoy a public healthcare system focused on treatment and resulting in some of the longest average life spans in the world (Boesveld, 2014). In his New York Times best-selling book *Being Mortal: Medicine and What Matters in the End* (2014), surgeon and author Atul

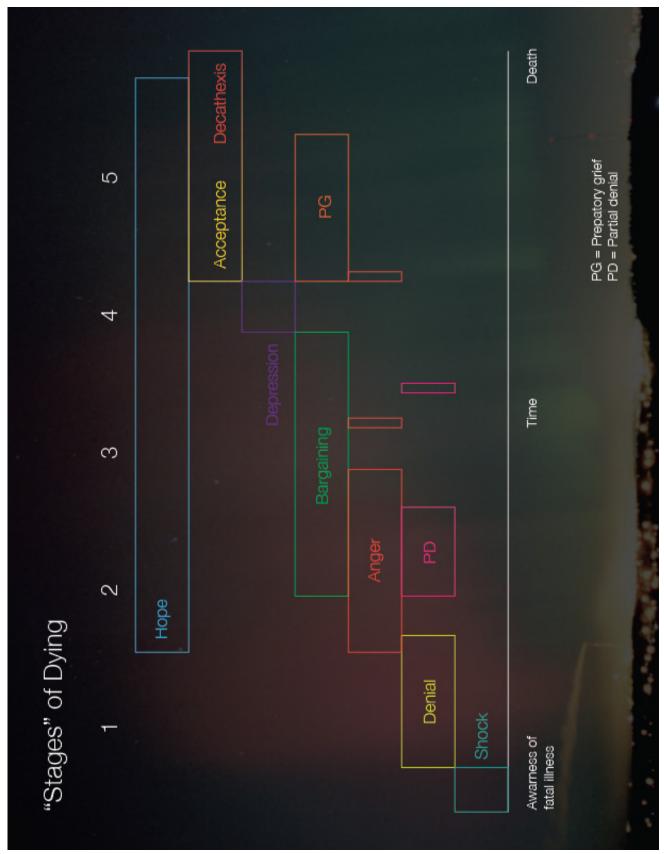


Figure 1: Adapted from The Five Stages of Dying (Kübler-Ross)

Gawande shares a poignant perspective on the medical system challenges with end-of-life care through anecdotal stories from his experience and practice. One of the most salient points in his argument is the continuous urge to 'fix' a life threatening health issue, even if this is not the going to provide the best quality of life for the patient in their remaining time. In his article for *The* New Yorker, "Letting Go", Gawande shares deep insight on our North American cultural perspective around saving lives with medicine and patient expectations and choice. "Death is the enemy. But the enemy has superior forces. Eventually, it wins. And in a war that you cannot win, you don't want a general who fights to the point of total annihilation." (Gawande, 2010). His storytelling technique encourages the enlightenment around fighting for life, at the cost of living a quality of life. He directs attention to mindfully making choices and ensuring you have a physician who can lead you in the right direction. "You don't want Custer. You want Robert E. Lee, someone who knows how to fight for territory that can be won and how to surrender it when it can't, someone who understands that the damage is greatest if all you do is battle to the bitter end" (Gawande, 2010). Through the vibrant storytelling

of his own patients and their struggles with making the difficult decision about their mortality, Gawande is able to give voice to our contemporary culture and expectations of medicine. Today, we find ourselves deliberately disconnected from the end-of-life cycle and it is this development of culture that is at the very root of contemporary views on death management.

Clifford Geertz a 20th century anthropologist believed that human life relied on culture for its growth and existence. The symbols created through culture were, he believed, central to the human development from the early ages. "Without men, no culture, certainly; but equally, and more significantly, without culture, no men." (Geertz, 1973, pg 49). These symbols, according to Geertz are the meaning we collectively create, that is the defining of culture. More recently, as Mike Featherstone described in Global Culture: Nationalism. Globalization and Modernity (1990), "culture is a way of summarizing the ways in which groups distinguish themselves from other groups. It represents what is shared within the group, and presumably simultaneously not shared (or not entirely shared) outside it" (Featherstone, 1990, pg 32). Canadian culture around death is

a mosaic of historical traditions from around the world, making us a unique blend that culminates in shared western values. The culture of Canadians currently has been to shy away from death and dying, asking professionals to handle the departure of our loved ones. But how exactly did we become so radically disengaged from death? Given Canada's short legacy (with the exception of indigenous peoples) as compared to other countries and cultures, where might the influence have come from that persuaded the population to see even discussing death as taboo? From the avoidance of conversations of death with ageing loved ones to the decisions at the end-of-life being made in the moment as opposed to with advanced consideration, we are quietly reinforcing the taboo. With Featherstone's definition in mind, we will first explore how our contemporary culture has been assembled by historic practices and events from sociological and anthropological frameworks. Historically, our western culture and attitudes have many roots in developing our current cultural context.

Phillipe Aries in his book *Western* attitudes toward death from the middle ages to the present (1974) seeks to give perspective on the contemporary

western attitude towards death by examining the historical events and traditions that led to current practices and perceptions. Examining previous centuries' accounts of death and dying, the author provides perspective on how attitudes toward death have changed during distinct periods of time. In his account of the period post 12th century which he refers to as "One's Own Death", Aries explores how both religion and one's own personal connection with nature created shifts in the perspective of death and a "deeprooted refusal to link the end of physical being with physical decay" (Aries, 1974, pg. 33). During this time, death was seen as a stage of life. The experience was not an end, but the evolution of being. Historian Jon Davies notes in his book Death, Burial, and Rebirth in the Religions of Antiquity (1999) that even previous to Aries insights, the ancient Egyptians likely also believed in life beyond the mortal world. "The Egyptian afterlife was seen as more life, not death, and life with negatives removed. Egyptian cadaver-preparation, funerary arrangements and architecture were designed to ensure this" (Davies, 1999, pg. 32). Although many religious beliefs might hold similar values today, there is not a predominant connection to afterlife in our Canadian context.

Perhaps most inherently linked to contemporary views on death are Aries' notes on what he describes as the period of "Forbidden Death", his examination of the 19th century movement toward hiding away from the gravity of the dying condition (Aries, 1974, pg. 86). During this period there was a distinct shift in 1930-1950 of people dying at home – as it had been for centuries – to dying at the hospital. Aries refers to this transition as the "hush up of death" (Aries, 1974, pg. 87), where society made the distinct decision to remove death from the realm of the living. Today the majority of deaths occur in hospitals, or more than 66% continuing this trend (Statistics Canada, 2012).

However, we are now experiencing a tangible counter-trend toward the effectiveness and repercussions of this cultural decision to institutionalize death. Many of the experts interviewed for this research direct attention to the displacement of our western connection to death as a result of the development of our current healthcare system after the American Civil War. "Today's funeral industry, which uses embalming (to prevent decay of the body), and concrete vaults, largely materialized from the desire of a generation of Civil War mothers to have their sons shipped

back home." (Shamma, 2010).

Capitalism plays a key role in this perspective, as death became a central focus of commerce and profit. Aries notes,

"It is not easy to sell something which has no value because it is too familiar and common, or something which is frightening, horrible or painful. In order to sell death, it had to be made friendly. But we may assume that 'funeral directors' – since 1885 a new name for undertakers – would not have met with success if public opinion had not cooperated."

(Aries, 1974 pg. 99).

As Aries discusses, 'Death as commerce and of profit' including the practice of embalming which he describes as also connected to the refusal to die, the livings' desire to visit a 'living' person and funeral directors taking a lead role as the "Doctors of grief" (Aries, 1974, pg. 100) in North America allowed for death to be 'treated'. "They presented themselves as simple sellers of services, but as 'doctors of grief' who have a mission, as do doctors and priests; and this mission, from the beginning of this century, consists in aiding the mourning survivors to return to normalcy" (Aries, 1974, pg. 99). Hannah Arendt, a political theorist and philosopher provides a

baseline perspective on the creation of our current culture. In her book The *Human Condition* (1958), she notes "Whatever touches or enters into a sustained relationship with human life immediately assumes the character of a condition of human existence. This is why men, no matter what they do, are always conditioned beings. Whatever enters the human world of its own accord or is drawn into it by human effort becomes part of the human condition" (Arendt, pg. 9,1958). From this perspective, we can understand that we are the reality that we have created. This reality, it could be argued, was developed by prior generations, and has more recently formed our cultural practice to be a reality that fears death. This research exploration will serve to shine a light on the shifting ground of the culture of death and dying in Canada, including innovative services and the generational context that is shifting our collective perspective and culture.

Ivan Illich, an Austrian Philosopher and a Roman Catholic Priest was an outspoken critic of western institutions including the healthcare systems inequities in the 20th century. In his work *Limits to Medicine* (1976), Illich begins with a provocative statement that

"the medical establishment has become a threat to health" (Illich, 1976, pg 3). He draws note to the downfalls of the "medicalization" of health by discussing the ingrained urge for growth in the healthcare sector as enterprise. Illich believes that society is on a dangerous course moving away from an earlier approach of self-determined health to entrusting all decision and care within the professional realm. In fact, he believes that western society has reached the state of an epidemic and that "the social commitment to provide all citizens with almost unlimited outputs from the medical system threatens to destroy the environmental and cultural conditions needed by people to live a life of constant autonomous healing." (Illich, 1976, pg 6).

In comparing Illich and Aries' portrayals' of the changing western attitudes toward death, authors Fontana & Reid Keene (2009) created a summary (Table 1) to compare and contrast the perspectives over the last millennium. The authors highlight that "one of the dominant themes in their work is the shift in death as a public affair, open to everyone, to a private affair, closed to children and the larger community" (Fontana & Reid Keene, 2009, pg 25).

In the research paper Death and dying in contemporary society: an evaluation of current attitudes and the rituals associated with death and dying and their relevance to recent understandings of health and healing, Nurse Stella Mary O'Gorman, reviews the current attitudes toward death and dying, based on Ivan Illich's model. In Figure 2, O'Gorman has expanded on Illich's model to represent the phases of which the contemporary Western perspectives have come to be shaped. In her foreword, O'Gorman notes, "... in the first half of the 20th century, society lost sight of the importance of rituals associated with death and dying and of the need for appropriate death education. Consequently patients and professionals alike found themselves unable to cope with the inevitability of death. Fear supplemented hope, and the health and well-being of society was deleteriously influenced." (O'Gorman, 1997, pg 1127). Our shift away from the rituals and rites of death were largely due to the rise of the medical profession. In reviewing the model, there are distinct shifts acknowledged in the religious relationship of death during the 15th to 17th century. Whereas previous to this period death was viewed as an intervention of God, during this time death became more independent

and autonomous. This was a sweeping shift in thought due to a "...readiness by the society of that time for a radical change in attitudes and for death to become a natural event." (O'Gorman, 1997, pg. 1129). During the industrial revolution, society came to desire good health and long life. The rise of wealth and the bourgeoisie created a focus on health to help increase economic growth. "The health of a nation became relevant factors in economic management. An apparatus ensuring the constant increase of a population's usefulness had to be organized. Death was regarded as an 'untimely event' when it came to those who were both healthy and old" (O'Gorman, 1997, pg. 1129). Today, we can still identify some of these values in our modern perception on death. The 19th century brought the rise in perception that doctors were authoritative in death management as the "outcome of diseases gave rise to the myth that they had power over death. The new powers attributed to the profession gave a new status to the clinician." (O'Gorman, 1997, pg. 1129).

As we moved into the 20th century a few critical shifts took place. The first was that health had become viewed as "a commodity undermining the unique

T	Death and Cultn	ulture		
S	Stages of Death	Historical Period	Characteristics	Sociological Relevance
	Illich			
۵	Dance of the dead	(300 - 1300)	Dancing on tombs with corpse to express the joy of life.	Death is with us through life.
ă	Dance of death	(1400 - 1500)	Dancing with skeletons.	Death is at the end of life.
В	Bourgeois death	(1600 - 1700)	Death is forestalled with help of medicine.	Death is related to social class.
D	Death and medecine	(1800 - 2000)	Death is moved to hospitals.	Doctors control death.
A	Aries			
T	Tamed death	(500 - 1100)	Death is a public affair.	Death is accepted as natural; nothing can be done about it.
0	One's own death	(1200 - 1400)	Death becomes personal.	Living a virtuous life will be rewarded afterwards.
T	Thy death	(1500 - 1700)	Death seen as a 'break' from everyday life, like love.	Romantic, emotional
ц	Forbidden death	(1800 - 2000)	Death is moved to hospitals.	Technical, private

Table 1 – Adapted from the summary of Illich and Aries' stages of death in Western societies (Fontana & Reid Keene)

spiritual and intellectual strength of the human race which enables them to rise to the challenges of death and dying." (O'Gorman, 1997, pg. 1130). Death became viewed as a failure of services and during this time society purposefully created distance from death. This is illustrated best by the use of euphemisms to describe the death of a loved one such as 'passed away'. Building from Illich's perspectives, O'Gorman contends that a 7th stage is inspired by Sweeting and Gilhooley's (1992) "social death", described in their article Doctor am I Dead? A Review of Social Death in Modern Societies. The social death is described by particular trends affecting the displacement of a dying person from the social context of community preceding a biological death. These trends include an increased life expectancy resulting in people living long enough to experience dementia, modern high-technology medicine enabling people to be kept alive for long periods in a comatose state to prolong life, as well as changes in the family structure leaving fewer family members to care for the dying at home creating a need for institutional care prior to death (Sweeting & Gilhooley, 1992, pg 265). This stage in O'Gorman's' model examines a surge in understanding the cultural differences in social

death and biological death. O'Gorman directs attention to the loss of rituals associated with death and dying as a result of the strong consensus built by the professionalization around death management. A shift in these rituals resulted in a departure from the primitive traditions and created the Western perspective we are familiar with today, where we rely more heavily on a healthcare system to lead, resulting in less of a social process (O'Gorman, 1997, pg. 1130). O'Gorman follows this with a proposed 8th stage being a "return to holistic concepts", describing a current state of education and awareness endorsing a reintegration of the understanding of death.

Almost 20 years after her work was published it can be argued that in contemporary Canada we are experiencing an enhanced 8th stage where we continue to experience changing attitudes about dying, as seen with the incoming national decriminalization and policy development around physician-assisted death. This distinct decision by the Supreme Court of Canada to allow medically qualifying terminally and/or mentally ill patients to access their decision to end-their-life would appear to be evidence of an incoming

tipping point in the cultural perception of death (Fine, 2015). The 8th stage is also becoming apparent in the innovations currently underway in death services. We are moving past traditional funeral practices being swift and sombre occasions with black dress codes in funeral homes and religious buildings towards celebrations of life, that include laughter and colourful clothing in the home or public event spaces. There are also shifts in burial decisions from the common practice of cremation, which by 2019, according to the Cremation Association of North America will account for 3 out of 4 burial choices (Cremation Association of North America, n.d.). Indeed, there is a movement towards more sustainable alternatives with "today, nearly 400 approved cemeteries, funeral providers and burial products are certified by the Green Burial Council including approved funeral providers in Alberta, British Columbia, New Brunswick, Ontario, Quebec and Saskatchewan." (Redman, 2014). The distinctly observable death phobia would seem to be in the early stages of unwinding as advance care planning becomes a focused promotion by the government and health care practitioners (Health Canada, 2008) and other private sector businesses.

Reflecting on our historical Canadian context, current western culture can also be understood through comparisons to other practices around the world. Views on death hold a variety of fundamental differences internationally. In her essay Displacing Suffering: The Relocation of Death in North America and Japan (1996), Margaret Lock compares and contrasts some of the challenges around perception of death. One area in particular is the legal framework and opinions around brain death as the determinate of death. "Thoughtful people recognize that while brain death, although clearly the nub of the debate, has a metaphorical significance that triggers a cascade of ideological repercussion reaching far beyond the medical world". (Lock, 1996, pg.235). Within the debate of determining death and potential consequences, Lock discusses the role technology strongly plays in the debate. "The history of technology has usually been transmitted as a heroic tale about the conquest of the enemy, whether it be human or the natural world - a narrative of progress, and of the betterment of humanity in general." (Lock, 1996, pg. 208). As we see in our current culture, there is an ongoing storyline about the value of progressive technology and how it helps to aid our lives. We marvel in

how we have come 'so far' with our understanding of the world around us through advances in technology. "Of course this dominant ideology has, for the past century at least, been accompanied by a counter discourse replete with ambivalence and warnings about the consequences of technology gone wild" (Lock, 1996, pg. 208). With the unprecedented advances of technology in healthcare, we have also developed an unwillingness to face death in parallel to our fears of it. Medical anthropologist Cecil G. Helman defines his area of work as ".... the study of human suffering, and the steps that people take to explain and relieve that suffering" (Helman, 2007, pg 1). Medical Anthropology is an important lens in examining the culture around death and dying. In a cross-cultural context, there appears to be a range of practices and techniques for funeral rites, and a myriad of beliefs determining the cause and effects of death. "Anthropologists studying the socio-cultural end of the spectrum have pointed out that, in all human societies, beliefs and practices relating to ill health are a central feature of the culture. Often these are linked to beliefs about the origin of a much wider range of misfortunes (including accidents, interpersonal conflicts, natural disasters, crop failures,

theft and loss), of which ill health is just one form." (Helman, 2007, pg 7). As Helman describes when comparing cultures around the world it is easy to observe a variety of responses and informed beliefs about the meaning of death. "In some societies the whole range of these misfortunes is blamed on the super natural forces, or on divine retribution, or on the malevolence of a witch or sorcerer". (Helman, 2007, pg 7). In fact death is reacted to and treated by a spectrum of actions crossculturally around the world. From traditional funeral rites to burial rituals, a review of other culture's approach to death reveals a very different reality and experience than the Western world. In their book *Celebrations of Death:* The Anthropology of Mortuary Ritual (1991), authors Metcalf and Huntington offer a journey into the variations across culture.

"What could be more universal than death? Yet what an incredible variety of responses it evokes. Corpses are burned or buried, with or without animal or human sacrifice; they are preserved by smoking, embalming, or pickling; they are eaten – raw, cooked, or rotten; they are ritually exposed as carrion or simply abandoned; or they are dismembered and treated in a variety of these ways. Funerals are the occasion for avoiding people or holding parties, for fighting or having sexual orgies, for

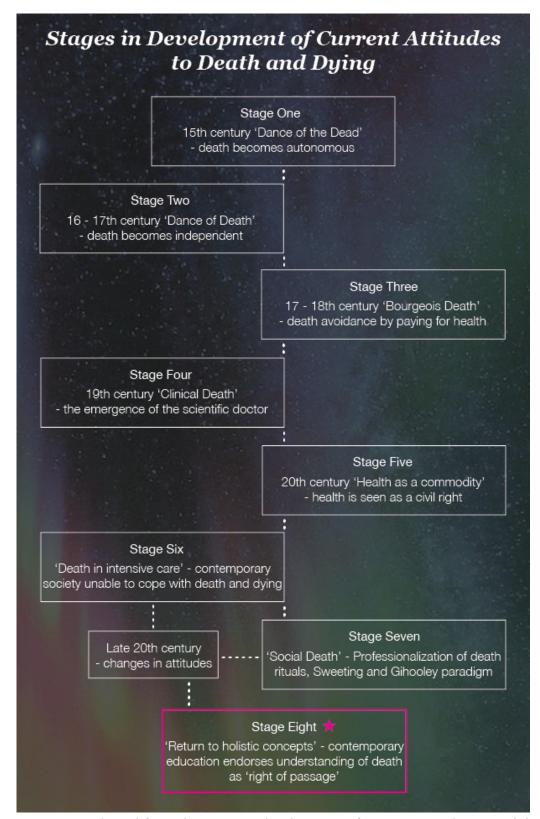


Figure 2 – Adapted from the stages in development of current attitudes toward death (O'Gorman), building on concepts from Illich and Sweeting & Gilhooley

weeping or laughing, in a thousand different combinations. The diversity of reaction is a measure of the universal impact of death" (Metcalf & Huntington, 1991, pg 24).

The Aboriginal populations of Canada have a distinct approach to death that does not resemble the more common fabric of Canadian cultural views. For example, research into the indigenous populations of Canada and the provision of palliative support noted that the Mi'kmaq Nation who lives in Atlantic Canada, views death as an extension of the journey of life, and a community event.

"The 'spirit road' is sometimes referred to by the Mi'kmaq as a journey that every person must take. It is not travelled alone, but rather in the company of the ancestors, linking the individual's journey with those who came before... End of life is not so much its own period but a continuation of the realities that there are many levels of existence. Combined with the importance of family and community, the perception of spirit is linked to a strong sense of faith in both the life and death process."

(Johnson, 2013, pg.65)

In comparison to the general population, the indigenous populations look at death not as a taboo, but as a part of the circle of life. In his Sociology

paper *Modern Death: Taboo or not Taboo?* (1991), Tony Walter, a professor of death studies directs attention to two distinct shifts that have contributed to our current western views on death. The first is the hippie period, followed by the green movement. On the hippies, Walter notes,

"The counter culture of the 1960's reacted against rationality, asserting that feelings (of all kinds) should be expressed, no repressed; and it reacted against hypocrisy, requiring me to 'be myself'. Though bereavement was doubtless far from the minds of early hippies, the implications for the dying and bereaved are clear. They should talk about their feelings. The old norm that it was courageous for the dying and their carers not to talk about what was happening gave way, and it became courageous to talk about it (Wouters, 1990)" (Walter, 1991, pg. 298).

The hippies in their revolt against the culture of their parents' generation found ways to break out of the "hush up of death" and shifted their openness to acknowledging their feelings and views on death. This would lay groundwork for decades to come. The green movement has also had a strong hand in our more recent zeitgeist around death. "A green consciousness, however is more at ease with our natural condition, is prepared

to see limitations on human culture for the sake of preserving natural processes, and is critical of a high-tech medicine obsessed with preserving life at all costs" (Walter, pg. 298). Our awareness of the environmental impact of our modern practices such as the carbon footprint of cremation along with scientific evidence of the impact of living human activities such as population increase and industrialization are changing our perspective. There are surmountable modern concerns about the impact of death and burial practice on the environment. As Good Magazine reported, "In the 1960s, many championed cremation as a more ecologically responsible, trendy alternative to burial. This was partially due to the actions of the Catholic Church, which lifted a centuries-long ban on the practice in 1963. Cremation numbers in the Western world rose sharply; from around 4 percent in 1965, according to the Cremation Association of North American, to more than 40 percent at present, with projections toward 50 percent by 2018." (Magidsohn, 2013). The preferred trend to cremate suggests a cultural belief that it is a more environmentally suitable practice than burial of a body, that in fact cremation is 'green'. However, many are taking a closer look at the practice of

cremation and its implications, as more truly green option begin to break into the marketplace. As Gary May notes in his article about the rise of green burial options,

"Traditional funerals and burials are anything but environmentally friendly. A typical cemetery buries 4,500 litres of formaldehyde-based embalming fluid, 97 tonnes of steel, 2,000 tonnes of concrete and 56,000 board feet of tropical hardwood in every acre of space. Add to that the tonnes of cut flowers and carbon emissions from mourners' vehicles. If you think cremation reduces your carbon footprint, think again: it's estimated a single cremation uses 92 cubic metres of natural gas - enough to supply the average Canadian home for 12.5 days - and releases 0.8 to 5.9 grams of mercury" (May, 2012).

And what about the current demographic structure within Canada and its affect on the perception of death and dying? The Baby Boomer generation, born between 1946 and 1964 have recently over taken the population of children in Canada. "Canada now has more seniors than children aged 14 and under. To be precise, there are 5.78 million seniors compared to 5.75 million kids." (Kirby, 2015). With this sizable group of ageing population there are legitimate concerns about the demand on the healthcare

system. As Walter notes,

"Blauner (1966) points out that before modem medicine and public health drastically reduced death rates, the vast majority of adults who died did so in the prime of life. They left behind a massive gap - social, economic, and psychological - especially for families who depended on them. In this context, belief in an afterlife could bring considerable comfort, while comprehensive deathbed, funeral and mourning rituals helped survivors come to terms with their loss and restructure their roles and relationships. In the modern world, by contrast, most deaths are of the elderly. Their children have grown up, become financially viable and derive emotional satisfaction from themselves having become parents. When gran dies, it may be sad, it may be the end of an era, but the gap she leaves has long been filled." (Walter, 1991, pg. 300).

Not only are Baby Boomers a large population segment with distinct and frequent healthcare needs, they are also a group who has defined various market changes based on their influence. As one Death midwife Cassadra Yonder offered in her interview with CBC News, Death midwives are gaining popularity and attention as Baby Boomers look for choice in dealing with their options around where and how to die. "We know that the Baby Boomers are a very strong and compelling consumer group who

demand choice. When they were going through having babies, we saw vast leaps and bounds in terms of improvements around the birth midwifery movement. So I think this is maybe a second wave of that" (CBC News, 2015).

But are we in the 8th stage of O'Gorman's' model as our perception on death and dying? Is there further evidence to reveal this momentum of change? What will that mean for the future of dying in Canada over the next two decades? A Report from the Vanier Institute of the Family titled *Death* Dying and Canadian Families (2013) notes that,

"While we might all hope to live forever, the fact remains that we will all die. No matter how active, healthy and vibrant we may be, death will still come. Only if we face the realities – as opposed to our desires and assumptions – can we prepare for the demographic challenges that lie ahead. Only then can we prepare for our own deaths and those of the people we love." (Arnup, pg 12).

There remains an urgent need to more openly acknowledge the shortcomings of our death phobia. Creating a broadly understood knowledge of our western fear and anxiety will serve to openly address some of the desires that are currently being unmet in the end-of-life process. For example, a large majority of elderly would prefer to die at home as opposed to the hospital. Yet, the removal of death from mainstream society and community leaves families and friends widely unprepared to assist their loved one in their preference. In parallel, our secular state has also shifted the realities of care and obligation. "While religion traditionally provided a focal point and a means through which people could support one another... declining religiosity has meant that fewer people can draw upon that support. Thus, community-based services, including expanded home care, fill an important gap in families' lives." (Arnup, 2013, pg 20). Culturally speaking, the emergence of palliative care and hospices has begun to bridge the desire to ensure pain management outside of a hospital environment while offering a more wholesome community experience. Although hospices are a more cost effective option than a hospital stay, they have also proven to be deeply valuable in terms of experience for the patient and their family. "The family members often describe the feeling of a burden being lifted, as they are able to rely upon professional care of nurses and personal support workers, and the care of volunteers. (Arnup, 2013, pg 12). In reviewing the 2015

Economist Quality of Death Index: Ranking Palliative Care Across the World, Canada ranks as 11 out of 80 countries in terms of five categories of assessment: healthcare, environment, human resources, affordability, quality and community engagement. Behind countries such as France. Australia and Germany, Netherlands, New Zealand and the first ranked, and often viewed as a palliative care pioneer - United Kingdom (Economist, 2015, pg 11). Interviews with experts further uncover areas of transition in values and perspectives around death management Canada. The following research will demonstrate the shifts underway to reveal a deep cultural change in the meaning of death and its practices moving towards a future stage of embracing, openly discussing and planning for the end-of-life. Through the use of methodologies including a horizon scan and the implementation of the three horizons theory, a vision of the future of death management in Canada will be communicated.



"It is not the end of the physical body that should worry us. Rather, our concern must be to live while we're alive - to release our inner selves from the spiritual death that comes with living behind a facade designed to conform to external definitions of who and what we are." - Elisabeth Kübler-Ross

Methodologies

THE RESEARCH WAS APPROACHED AND conducted over three phases. The first stage of data elicitation occurred through an expert panel event, a participatory workshop, a literature review and interviews with experts. The first stage was an opportunity to gather insights on the roots of the research and build a compelling understanding of the current state of the culture around death and dying in Canada. In the second stage, data analysis and synthesis was conducted through a horizon scan using a STEEP+V framework and causal layered analysis techniques. These techniques were selected in order to ensure that deeply seeded challenges with death could be analyzed and understood in a broad context. The third and final stage of synthesis and extrapolation was carried out with the use of the Three Horizons framework, enabling visions of the changing future.

Data Elicitation

The research exploration began with a variety of inputs. In this stage, the researcher collected primary research with experts through event and workshop participation, as well as conducted a literature review. The research journey began with attending an expert panel event. This served to understand the current conversation and become immersed in the discussion within death services, as well as source potential experts who might be available and interested in participating in the research.

The initial expert panel was Beyond the Debate: The Future of Physician-Assisted Suicide (June 2015).

The Institute of Medical Science at the University of Toronto assembled academics, health care professionals, and ethicists to shed light on the controversial issue of physician-assisted death, and discuss the significance of what the Supreme Court ruling to allow for physician-assisted death means for the Canadian health care system and society.

The panel was moderated by Lawyer and Doctor Richard Minster and included the following panellists:

Jeff Blackmer, MD, MHSc, FRCPC Vice-President, Medical Professionalism Canadian Medical Association Associate Professor | University of Ottawa

Jean Echlin, RN, MScN
President, Euthanasia Prevention
Coalition
Adjunct Associate Professor, Faculty of
Nursing | University of Windsor

Kerry Bowman, PhD Clinical Ethicist, Mount Sinai Hospital Bioethicist, Joint Centre for Bioethics | University of Toronto

James Downar, MDCM, MHSc, FRCPC Co-Chair, Physicians Advisory Council | Dying with Dignity Canada Assistant Professor, Divisions of Critical Care & Palliative Care | University of Toronto

The event served to shine light on the tensions that exist within the idea of enhancing the current healthcare system to include physician-assisted death. Some of the more contentious and notable discussions lay within the concerns for vulnerable populations – namely ageing and disabled persons – and also within the apprehension of reframing the medical profession to include death as a service of care. Fears over doctors' moral opposition to helping people die rather than treat illness and disease were central to the debate. With current ageing populations' demands evolving, the shift in our cultural understanding of medical 'care' to include death will premise a

dramatic shift in the way in which we understand death and deal with the cultural phobia surrounding end-of-life.

The research carried on through a participatory event workshop titled, Living & Dying through Change & Transformation (August 2015). The workshop was hosted by OCAD's Design with Dialogue events, which is an open community of practice to lead organizational & community change through participatory design, strategic dialogue and emerging facilitation methods. Led by Vanessa Reid, the co-founder of Living Wholeness Institute, the working session was attended by 25 people from a variety of professional backgrounds and focused on exploring and understanding the fears and disturbances that come up in transitions, such as the end-of-life. The workshop discussions revolved around the central question of 'making sense' of the lifecycles in our individual lives, organizations, and systems. Through discussion, the group compared ideas and experiences from the times of personal transition and growth to understand the cultural contexts of our meanings of 'endings'. The workshop resulted in a heightened awareness of the cultural norms within our understanding of death and dying, and

the fear many have of the end-of-life. The workshop offered a first glimpse at admission that the culture of death management as potentially broken and un-sustainable reality.

The next stage of research involved an extensive literature review that included relevant books, journals, research studies and media articles pertaining to death and dying. This data elicitation was sourced through referral and desk research, to provide perspectives from the following frameworks; Anthropology, Medical Anthropology, Sociology, Psychology, Philosophy, Historical, Political Theory, Nursing, Archaeology, Psychiatry and Thanatology. The array of frameworks was necessary in order to ensure a rich understanding of death and dying as it pertains to the development of our cultural perspectives. The literature review diverged in the offset to explore the vast mystery of death and dying and in the final months converged to provide contextual background of historic practices and events that might have led to the development of our current culture of death phobia.

The final stage of data gathering was through interviews with experts. The outreach was conducted directly through email or other private contact information, which was obtained through referral. Each participant was asked to sign a release document outlining his or her participation. Participant interviews were audio recorded and were conducted either in-person, by telephone or Internet conference. The selected group of 15 experts included professionals from a wide range of fields, all connecting to death management. As with the literature review, the variety of fields (Figure 3) - including policy, healthcare, funeral services, grief counselling, and burial practices - provided a well-balanced research sample. With approval from the Research Ethics Board at OCAD University, the experts were contacted. The expert interviews were a predominant part of the research and were conducted with individuals mostly in Canada, and supplemented by innovators and leaders in the United States, Italy and Switzerland. With the research focused on Western cultural attitudes, interviews with experts from the United States had considerable value in framing the Canadian context. With some consideration to our notable differences in the healthcare approach between Canada and the United states. many of the cultural norms discussed were similar perspectives to the

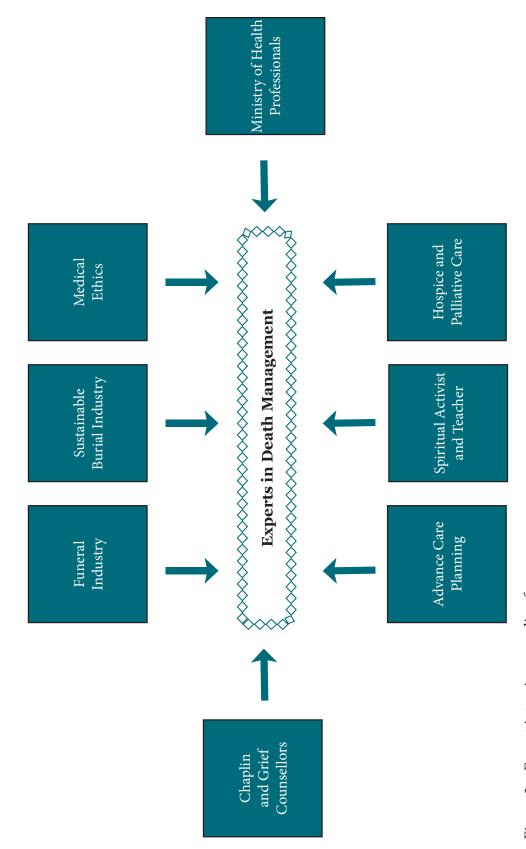


Figure 3 – Expert interview sampling frames

Canadian experience described by experts from Canada.

Each expert was asked to comment from their perspective and domain on a series of 5 questions regarding barriers, unmet needs and innovations.

- i. Tell me about the nature of your work.
- ii. What are the barriers in death management?
- iii. What changes do you see happening currently in death management?
- iv. What service needs and desires of clients and patients are currently being unmet?
- v. What are the areas of innovation within death services currently?

Data Analysis And Synthesis

In the initial stage of data analysis a horizon scan was conducted to identify changes in the landscape and gather insights to form a deeper understanding of the cultural context of death and dying. The STEEP+V thematic framework – Social, Technological, Environmental, Economic, Political, Values - was used to ensure a balanced understanding of the forces affecting

the culture of death. As an extrapolatory method, horizon scanning is a technique to determine changes that are occurring as well as what is constant in the residing environment. This method helps to understand the margins of current assumptions and reveal signals to current thinking that can challenge these assumptions and provide the background to develop a vision of the future (OECD, n.d.). The horizon scan process uncovered the themes at play and revealed a set of key drivers that are currently impacting the changing perceptions of death and dying in Canada.

The Causal Layered Analysis framework (Figure 4) was employed to reveal the key trends and drivers that might shape the following decades. According to Futurist Sohail Inayatullah, causal layered analysis (CLA) is theory of knowledge and a methodology often used for creating more-effective policies and strategies (Inayatullah, 2014). CLA is undertaken to explore the root causes and reveal the deepest, metaphorical levels of current changes. For this research, the CLA was informed by the key drivers and trends identified in the horizon scanning and expert interviews, to uncover the key driving forces and their relationships to each other. The

application of the CLA framework revealed that there is a potential to evoke change in the 'Worldview' perspective of Canadian society, along with the 'Causes' and 'Problems'. Shifts in these upper layers might result in future changes of the 'Metaphors and Myths' that surround the cultural fear of death in contemporary Canada.

The CLA was a critical aspect of undertaking the cultural analysis of death. The systematic examination of the relationships of the layers identified possible paths of the evolution of stages and provided a framework oriented around dominant ideology shifts.

Data Synthesis and Extrapolation

Finally, the Three Horizons framework was used to provide an orientation around the dominant shifts in the current cultural ideology around death and dying in Canada. The implementation of the three horizons allowed for the research to envision an evolution of changes over time, and the movement and negotiation that might take place in the interim. Building from the first horizon, or the current state, a second and third horizon was developed to demonstrate the movement and negotiation required for the adoption of a different cultural orientation over

time. The key drivers gathered in the CLA stage of the research, as well as the consensus of themes from the experts and literature review, pieced together to reveal a plausible third horizon that might provide a more sustainable cultural view on death and dying in Canada. With the expert interviews revealing some consensus in responses, even when professional experience varied, it became obvious that we are moving toward a different and more ideal state.

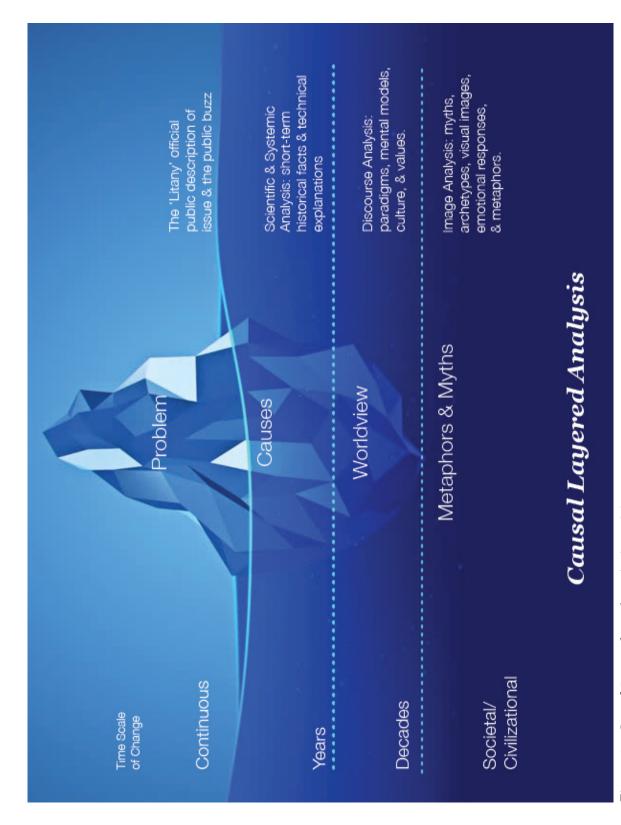


Figure 4 - Causal Layered Analysis (Adapted from Inayatullah) is undertaken to explore the root causes and reveal the deepest, metaphorical levels of current changes.



"The future is here – It's just not evenly distributed."

- William Gibson

Findings

EXPERT INTERVIEWS

The expert interviews brought forth compelling thoughts, emotions and observations around the current state of death and dying in Canada. A collection of highlights from the interviews is provided as a means to understand the divergence and convergence of perspectives.

♦ The increased value and public interest in green burial techniques

"I did a lot of thinking about how our cities are lacking in meaningful places for our dead. In the countryside you might have green burial ground which is a beautiful concept and way to honour the deceased, but it's really a rural option not for the urban centres. I started to think about what would be an appropriate urban system that would honour the people we are saying goodbye to but also environmentally speaking." - Katrina Spade is the Founder and Executive Director of the Urban Death Project

"I started this project as a thesis project in architecture. I was an older student with a few young kids, and I blame them for making me see that I was going to die one day because they were growing up so fast. I wondered what would my family do with my body? I am not religious so I looked though the options available and was right away unimpressed by their environmental impact and how non-meaningful and impersonal they were." - Katrina Spade is the Founder and Executive Director of the Urban Death Project

"The idea is gardens growing from the soil reduced from the dead. Its part of the human experience so that you can come back and experience a living part of your loved one." - Katrina Spade is the Founder and Executive Director of the Urban Death Project

"I find traditional burial is loosing traction due to environmental awareness and the different ways you can dispose of your body." - Amy Pickard is the Founder and Operator of Good To Go!

"Tracing the argument about climate change is very relevant. Forcing us to think of the planet as a single unit and the consequences of our actions and others around the globe like never before. That is a real mind bender.... And there is some sense that we have really screwed things up." - BJ Miller, Zen Hospice is the Executive Director, Zen Hospice Project in San Francisco, California and a Palliative Care Physician

"If I am a person who cares about my carbon footprint and I hear that cremation will add carbon into the air worth a road trip across the country. If I am someone that cares about the environment and hear that my embalmed body will leak carcinogens into the ground water. There are other options." - Kathi Kelly is a Death Doula, Chaplin and Owner of Going Home - midwifery to the dying

"Reality is that the cremation rate is skyrocketing and has been for the last 20 years around the world. Part of it is that the cost of burial is expensive." - Brad Milne, Founder and Partner of Better Place Rest

♦ A surge of public and government interest in advance care planning

"Death has been hijacked by "the man"...
the corporate funeral industry. No one
should have to go bankrupt by burying
a loved one." - Amy Pickard is the
Founder and Operator of Good To Go!

"Most people find that they have to do death planning under a traumatizing circumstance. The message I'm trying to get out is that you should do it when you are NOT undergoing trauma. It's taking the uncertainty, fear, resentment, guilt and transmuting those feelings into peace, love and knowing. This provides an emotional space to focus on the things that are important." - Amy Pickard is the Founder and Operator of Good To Go!

"A big gap or challenge that the
Supreme Court ruling touched on in
Canada is advanced care directives." Amanda Baine is the acting Manager of
the Strategic Policy and Mental Health
Secretariat Unit in the Ministry of
Health and Long-Term Care's Strategic
Policy and Planning Division

"We don't have much of a way or habit of thinking about our own death." - BJ Miller is the Executive Director, Zen Hospice Project in San Francisco, California and a Palliative Care Physician

"Death and dying is a design decision. If you choose the status quo, you may not think you are designing your death, but you are." - Katrina Spade is the Founder and Executive Director of the Urban Death Project

♦ A need to build awareness of the existing and changing options and resources in death and dying

"Its very important that the thing that is going to happen to all of us. The disconnect is massive. If you look back 100 years ago, death was happening at home. People were digging their family member's graves and having the bodies cared for at home." - Andrea Warnick is an Educator and Grief Therapist

"A lot of people had never heard of a death midwife." - Amy Pickard is the Founder and Operator of Good To Go!

"First of all doulas. Dying really is a natural process and things get complicated when we get in there and mess things up. Doulas are an innovation because the majority of deaths are uncomplicated. When there is an adequately prepared family and care system it can have a big impact. That is the type of caregiver that can truly impact the system and address the grief." - Dr. Jeff Myers is a Palliative Physician at Sunnybrook Health Science Centre and for the past 9 years has been Head of Sunnybrook's Palliative Care Consult Team

"More people die sedated now than ever before." - Stephen Jenkinson, MTS, MSW, Spiritual Activist, Teacher, Author and Ceremonialist

"You make a revolution by democratizing wisdom and knowledge. That means that a death phobic cultures principle responsibility is to learn dying, not what to do about dying."

- Stephen Jenkinson, MTS, MSW, Spiritual Activist, Teacher, Author and Ceremonialist

"There are not many palliative care specialists in Canada which can make accessing specialists with specific training a challenge. Access to the right kinds of resources (equipment, professional services, etc.) can also

be a barrier." - Michael Hillmer is the Director - Planning, Research and Analysis Branch at the Ontario Ministry of Health and Long-Term Care

"There is a lot to make beautiful here....
but the little caveat here is make sure
to make space for all the stuff that you
can't possibly understand or know."
- BJ Miller is the Executive Director,
Zen Hospice Project in San Francisco,
California and a Palliative Care
Physician

"What we do at Undertaking LA is very much the same as everyone else many ways. We offer burials, cremations, and funeral services. We are open to any and all who would like to use our services. We are different in the way that we highly encourage family interaction with the dead body. We think that instead of having the body rushed off to the funeral home to be embalmed that you take time to sit with it at home, placing cooling blankets or dry ice next to the body to keep it cool when necessary. Then when you are ready you can lightly wash the body, meaning take a bowl of water and washcloths and wiping the body down, and then dressing it and preparing it to be casketed." - *Amber* Carvaly is the Owner and Operator of

Undertaking LA

"So many things that can go wrong with a home birth and yet we have embraced it. A death midwife cant really make a mistake because the death has already happened...so what is the problem with accepting it?" - Kathi Kelly is a Death Doula, Chaplin and Owner of Going Home - midwifery to the dying

"Death doula is not new. It's very old. A revisiting of what has been around the world. But there are more tools of the trade." - Kathi Kelly is a Death Doula, Chaplin and Owner of Going Home - midwifery to the dying

"One barrier would be lack of information. People have a lack of information about the dying process. How to know where one is during the process. How to mentally and spiritually prepare for death. Lack of information among families about how to talk about death and the supports through OHIP about how to support them. If someone says they want to die at home they aren't sure. There is so much information missing." - Linda Hochstetler is a Social Worker and Specialist in Death & Dying

"The health care systems in Canada are beginning to transform themselves

towards a more community-driven model. These models are usually built on a foundation of primary care, community supports, and home care. Healthcare policy planners are aware of the changes that need to happen to better support people as they age and the associated medical and social conditions that occur. This transformation is not fully complete yet "- Michael Hillmer is the Director-Planning, Research and Analysis Branch at the Ontario Ministry of Health and Long-Term Care

"Many people are watching their Baby Boomer parents who are actually not dying well. When you watch someone not die well you get that there are other options. If you look at weddings and how they were prescribed and now what they are. It's this generation that will change It." - Linda Hochstetler is a Social Worker and Specialist in Death & Dying

"What we need to do is make a bigger fuss over dying and death, by doing so make a more conscious decision." - Katrina Spade is the Founder and Executive Director of the Urban Death Project

♦ The incoming physicianassisted death legislation shifting perception of healthcare

"We tend to spend 99% of our time which will effect a small percentage of people — assisted dying — rather than the bigger issues like palliative care that will affect everyone." - Dr. Jeff Blackmer Dr. Blackmer currently serves as the Vice President, Medical Professionalism at the Canadian Medical Association

"As you know, the Supreme Court made a decision recently for Euthanasia. Everyone is playing 52 card pick up. And what is happening behind the scenes is that everyone is developing their own protocol. Here is the question... where is the expertise coming from? What will it be rooted it? What could it be rooted in other than the pervasive death phobia that I am talking about." - Stephen Jenkinson, MTS, MSW, Spiritual Activist, Teacher, Author and Ceremonialist

"Euthanasia is the death culture's solution for its own terror. You writing a prescription for your own addiction will always include your addiction."

- Stephen Jenkinson, MTS, MSW, Spiritual Activist, Teacher, Author and

Ceremonialist

"One of the challenges that we are experiencing is trying to balance what patients are expecting and asking for versus how physicians see their role." - Amanda Baine is the acting Manager of the Strategic Policy and Mental Health Secretariat Unit in the Ministry of Health and Long-Term Care's Strategic Policy and Planning Division

"The perfect indication that the tides are changing is captured in this ruling (re: Supreme Court decision on Physician-assisted death)." - Amanda Baine is the acting Manager of the Strategic Policy and Mental Health Secretariat Unit in the Ministry of Health and Long-Term Care's Strategic Policy and Planning Division

"The biggest change is the supreme court's ruling on physician assisted dying and giving the provinces a year to enable legislation to define what that means in each province. This is the biggest change in that landscape in the last year. An incredible array of individuals and organizations (medical societies, regulatory colleges, allied health professionals, think tanks, academics, etc) have been very active in this space. The file is incredibly

complex." - Michael Hillmer is the Director - Planning, Research and Analysis Branch at the Ontario Ministry of Health and Long-Term Care

"Choice is the big thing that is changing. People can say enough is enough and are able to come out of the closet and receive the end with blessing." - Kathi Kelly is a Death Doula, Chaplin and Owner of Going Home - midwifery to the dying

♦ Death phobia as a cultural norm

"The reality is that in this day and age we are so disconnected from dying as an experience". - Andrea Warnick is an Educator and Grief Therapist

"We have come to a point where death has become highly medicalized and people aren't familiar with it and we often don't see it". - Andrea Warnick is an Educator and Grief Therapist

"We need to change the cultural narrative of how we view death." - Amy Pickard is the Founder and Operator of Good To Go!

"We have always placed emphasis on the cure and see death as a failure and now we see that shifting." - Dr. Jeff Blackmer Dr. Blackmer currently serves as the Vice President, Medical Professionalism at the Canadian Medical Association

"The end of life belongs to one of the fields (like birth or marriage) in which historically the human beings have spent their skills, their knowledge, definitely their "arts", to represent their culture. This is especially true in the ancient societies, especially in the prehistoric or in the primitive one. Now we often delegate entirely this matter to the religion or better to the established institutions, also if there are no more representative of our cultural references. This happens because modern society put a taboo on the theme of death. So we think that there are barriers, and they are cultural and social. This stop is reflected in business death management too." - Capsula Mundi is the first Italian project created to promote the realization of green cemeteries in Italy

"In the old days, it was normal for people to pass away at home. There were three, maybe four generations living under one roof. And when the old ones got old-old, the young ones looked after them, cared for them until they died at home. Furthermore, up until about 80 – 100 years ago, it wasn't the doctor who came to the bed of a dying person. They stayed away once they saw that there was nothing much more they could do. It was the pharmacist coming to the bedside, bringing medication for easing death. With the development of the modern school medicine, and intensive care, this changed. Today, we have "done away" with death and suffering and "institutionalised" it, put it behind closed doors of hospitals and hospices. There are no pharmacists, but special clinicians and/or palliative care clinicians at the death-bedside. Our Western "civilised" and "modern" society has lost touch with the simple fact that life is a come-and-go and that death is just a normal thing and a part of life just as much as birth. Making a link to giving birth: whilst for many years it was recommended to women to give birth in clinics, there is now a bit of counter-movement, of women preparing and giving birth with a midwife at home, just like it was normal in the old days." - Silvan Luley, is the Manger of *DIGNITAS*, a not-for-profit member's society to live and die with dignity

"The background unfolds against a backdrop, a culturally endorsed, culturally enforced, culturally propagated death phobia that is so un-repented and so pervasive that it is in fact hard to recognize. It's easy to recognize among the slice of the population that is actively 'refusing to die'. The death phobia in fact is a cultural norm. When you develop eyes to see it, you see it in a lot of places that would not recognize themselves to be afflicted by such a thing. The death trade itself is a corroboration and collaboration of the culture and what the culture endorses." - Stephen Jenkinson, MTS, MSW, Spiritual Activist, Teacher, Author and Ceremonialist

"If we all get good at dying we wont have end-of-life care, we will have life. We will have sanity. We will have the end-of-life as part of life. We won't have a specialization called end-of-life care, because it will be taught to you throughout life." - Stephen Jenkinson, MTS, MSW, Spiritual Activist, Teacher, Author and Ceremonialist

"Looking at mortality...there is a sense that our society has sort of lost its way." - BJ Miller is the Executive Director, Zen Hospice Project in San Francisco, California and a Palliative Care Physician

"From a population point of view, from

a citizen point of view, the common themes are the decay of traditional family structures. We have become a more secular society. As a secular society, you don't inherit a batch of rituals that ease the angst." - BJ Miller is the Executive Director, Zen Hospice Project in San Francisco, California and a Palliative Care Physician

"There are plenty of people who will say they are not afraid to die. I do not believe them. I think that if you say you are not afraid there is some sort of latent denial. I would be willing to believe a person who says that they have "made peace and accept that they will die." as that contains a wholly different logic and reasoning in the answer. I have trouble believing that in a culture that is fascinated with the macabre, such as horror movies, mass murders, or just basic television like CSI, that we are afraid of the dead body. That idea is merely a placeholder for fearing death. I think that the fear of death comes from within us and our own personal fears that there could be nothing, and I think that it is also so completely culturally entrenched that it is almost impossible to separate and find it's root." - *Amber* Carvaly is the Owner and Operator of Undertaking LA

"Lots of other cultures do better than we do. We have been taught to keep our distance." - Kathi Kelly is a Death Doula, Chaplin and Owner of Going Home - midwifery to the dying

"I lead death cafes to increase peoples comfort with talking about it." - *Linda Hochstetler is a Social Worker and Specialist in Death & Dying*

"People don't even know they have a death phobia. It's not even conscious. If you ask the average person they wouldn't even know." - Linda Hochstetler is a Social Worker and Specialist in Death & Dying

"Death is not a failure. We fail if we don't think and talk about it in a way that is mindful and respectful." - Dr.

Jeff Myers is a Palliative Physician at Sunnybrook Health Science Centre and for the past 9 years has been Head of Sunnybrook's Palliative Care Consult Team

"Culturally we need to go to a larger intergenerational involvement of dying and death. We need to involve little kids in the process. In Canada we don't do this and it is traumatizing for kids not to see death. It can become so much more generally accepted and have more

personal experience with it." - Linda Hochstetler is a Social Worker and Specialist in Death & Dying

"I agree there is a death phobia. This is a totally personal opinion but when I look at the burial options they are not inspiring. A lot of them don't inspire conversation about the end of someone's life." - Brad Milne, Founder and Partner of Better Place Rest

♦ A growing need to invest in palliative and hospice care

"I do think there is a push right now - likely to do with the Baby Boomers - of how they want death to look. More people think that they want to be dying at home. More people being proactive about advance care directives. Certainly the government has become acutely aware of the costs involved and creating public campaigns to raise awareness. From an economic position, it's a lot cheaper to have people dying at home." - Andrea Warnick is an Educator and Grief Therapist

"We find ourselves at a time when enough evidence has been published in peer reviewed journals outlining the benefits of palliative care. Up until this point, palliative care has not been a formally recognized speciality or adequately resourced as compared to other areas of healthcare" - Dr. Jeff Myers is a Palliative Physician at Sunnybrook Health Science Centre and for the past 9 years has been Head of Sunnybrook's Palliative Care Consult Team

"The same people who specialize in treating people's diseases are often caring for people as they die... and often don't have the training to do it." - Andrea Warnick is an Educator and Grief Therapist

"In parallel to the strong evidence of the positive impact of palliative care on patient outcomes, with high quality comes increased value...systems will also happen to save a lot of money. When a have patient is adequately informed about their illness, the tendency is to decide not to pursue treatments and care directions that are more aggressive, like going into the ICU." - Dr. Jeff Myers is a Palliative Physician at Sunnybrook Health Science Centre and for the past 9 years has been Head of Sunnybrook's Palliative Care Consult Team

"The biggest barrier is access to palliative care. This is slowly improving.

One of the silver linings to all the discussion around assisted dying is more conversation that people are having about accessing a 'good' death." - Dr. Jeff Blackmer Dr. Blackmer currently serves as the Vice President, Medical Professionalism at the Canadian Medical Association

"Seniors care, palliative care are in the news more and that is because of Baby Boomers. It is a lot more top of mind. A whole generation is on the cusp of having to make this decision." - Amanda Baine is the acting Manager of the Strategic Policy and Mental Health Secretariat Unit in the Ministry of Health and Long-Term Care's Strategic Policy and Planning Division.

"Palliative care is going from nonexistent to something that everyone is talking about." - Michael Hillmer is the Director - Planning, Research and Analysis Branch at the Ontario Ministry of Health and Long-Term Care

"We know that palliative care is a speciality that comes with all sorts of training requirements." - Michael Hillmer is the Director - Planning, Research and Analysis Branch at the Ontario Ministry of Health and Long-

Term Care

"Doctor assisted suicide is only important to a very small group of people....some of my clients are interested in it and their biggest challenge is their faith in the palliative care system." - Linda Hochstetler is a Social Worker and Specialist in Death & Dying

"The system is not broken, it is so incomplete. The system is so inadequate for what is needed. The cost to keep someone in the hospital is phenomenal. Financially it is a no brainer, we need to shift." - Linda Hochstetler is a Social Worker and Specialist in Death & Dying

Reviewing the responses in the expert interviews in Table 2, a pattern of reinforced themes are consistently revealed in the barriers, changes and innovations noted by the individuals, including;

- The increased value and public interest in green burial techniques
- A surge of public and government interest in advanced care planning
- A need to build awareness of the existing and changing options and resources in death and dying
- The incoming physician-assisted-

- death legislation shifting perception of healthcare
- Death phobia as a cultural norm
- A growing need to invest in palliative and hospice care

Expert interview	Domain / Experience	Q2 - barriers in death management	Q3 - changes currently underway in death management	
Katrina Spade	Urban Death Project, Founder	access to affordable burial services		
		access to green burial		
Amy Pickard	Good to Go!, Advance Care Planning (USA)	corporate funeral industry	humanization of death	
		bankruptcy at death awareness of options	I	
Andrea Warnick	Grief counselor, registered nurse	disconnection from the death experience unfamiliarity with death due to medicalization high expense of dying lack of training specific to death in medical practitioners	increase in desire to die at home	
Dr. Jeff Myers	Head of Palliative Care Sunnybrook Hospital, Palliative Care Physician	greater investment in palliative care	baby boomers interest in mindful decision making around death	
		access to palliative care	focus on intention of advance care planning	
			focus on peoples values in their decision-making about death blossoming movement to combine palliative care and public health	
Dr. Jeff Blackmer	Vice President, Medical Professionalism at the Canadian Medical Association	access to palliative care	shift in conversation around death and dying in the medical profession	
		training at all levels for physicians patients being proactive to seek guidance and understand their options referring to palliative care earlier on in the process of dying		
Capsula Mundi	Burial Services (Italy)	death taboo	shifts in practices to deal with barriers - i.e. cremation because of	
		disconnection with death and culture	the lack of space	
Silvan Luley	Manager, Dignitas (Switzerland)	the financial cost of dying and becoming old	advocacy around the choices for death	
		power of choice (personal or state) patients not being taken seriously death taboo		
		institutionalization of death disconnection from the death experience as part of the life cycle		
Stephen Jenkinson	spiritual activist, teacher, author and ceremonialist	the power of the death trade	Physician Assisted Dying (PAD)	
	and colomonation	death phobia as a cultural norm lack of awareness around options and dying well		

Q4 - unmet service needs and desires	Q5 - what are the areas of innovation currently?	
	making death a more conscious decision	
advance care planning	brining humor and discussion to death	
exposing children to death/dying and allowing their participation awareness of resources to assist in death	fostering connection with the dead instead of severing ties aftercare options for the dead	
updated physician training around death to balance giving hope and discussing and informing death	death doulas social media conversation	
scaling of services to reach all Canadians	Physician Assisted Dying (PAD)	
	,	
	green burials	

the unwillingness to examine death becoming good at dying phobia

Table 2 – Expert interview analysis

Expert interview	Domain / Experience	Q2 - barriers in death management	Q3 - changes currently underway in death management	
Amanda Baine	Senior Policy Advisor, Ontario Ministry of Healthcare	patients wanting to be led and doctors wanting patients to lead the dialogue	Physician Assisted Dying (PAD)	
		comfort in discussing death	More news profile and discussion about the ageing population	
Michael Hillmer	Director of Research, Ontario Ministry of Healthcare	dying at home is complicated - not enough practitioners and resources	Physician Assisted Dying (PAD) and decriminalization of assisted death	
		propensity to prolong life healthcare system and resources to deal with the aging population access and resources for palliative care		
Dr. BJ Miller	Executive Director of Zen Hospice, Palliative Care Physician (USA) thinking of death as a problem lack of thinking about our own death		moving from the current disease centric model to patient centric thinking	
			increase in dialogue and awareness around death and dying	
		infrastructure for an ageing and dying population payment structure death phobia		
Amber Carvaly	Mortician & Service Director Undertaking LA(USA)	death phobia	increase in cremation (less costly)	
		awareness and education from		
		industry and individuals		
Brad Milne	Better Place, burial services	decision making on burial happening strictly in funeral homes	increase in cremation (less costly, less space)	
		death taboo	desire for change from millenials	
		death phobia		
Linda Hochstetler	Death Social Worker	lack of information about the dying process	death cafes	
		lack of awareness of services for	advance care directives and	
		dying unconscious death phobia	planning gen x, y and millenials are going to do death differently (after seeing	
		lack of exposure for young people with death	baby boomers not die well)	
		lack of experience with death (institutional)		
1 1	2 1 2 1			
Kathi Kelly	Death Doula	Advance directives Public awareness and advocacy	green cemeteries home deaths	
		Death Denial, anxiety Lack of education	home funerals	
		Myths that we live - lung cancer death means they must have been a smoker, they got what they deserved Preparation and education for doctors transient families - leaving care to one member institutionalization of death		

movement to choose wisely in treatment and palliative care

gratuitous suffering from a complicated healthcare system

shift to implement what we know already works and making it more accessible

communication - patients being heard and asking the appropriate questions coordination of care - Different doctors having different specialties and not being pulled together

reward caregiving in a real way

mindfulness

infrastructure

awareness of options

social media to increase dialogue around death

personalization

movie nights in mortuaries

services that appeal to millenials less money, more open minded than older generations choice of memorial capsula mundi

Canada is more advanced in burial regulation than other countries

home care support

hospice care and identifying the patients and flowing them into the care facility

investment in caring for people at

home

intergenerational involvement of death and dying

Physician Assisted Death (PAD)

Funeral and ceremonial innovation around celebration

slow death movement' (people allowing themselves to grieve and experience the feelings) green burials

families washing the bodies of the dead

autonomy in dying at home pain control/management investment in spirituality rights for same sex partners, foster parents, best friends, neighbors, etc. who are not next of kin death doula tool kit green burial options

Horizon Scan & Causal Layered Analysis

The horizon scan utilized the data from the desk research and expert interviews to show a number of trends at play. The horizon scan implemented the STEEP+V framework (Table 3), to synthesize of all data inputs. Themes and events from expert interviews and literature reviews were collected and gathered into the frames of Social, Technological, Environmental, Economic, Political and Values and revealed a list of social ideals developing in the culture of death management. The horizon scan data was used to inform an image of the future by understanding the variety of current trends in play. Each of the trends contributed pieces to forming the distinct notion of a radical shift underway. The forces that could move Canadians into a different and more desirable future state, unwinding from our current death phobic culture. This baseline understanding revealing factors shifting in the current environment that would affect the development of the three horizons model.

	STEEP+V Framework	Key Driver
Social		
•	Urbanization (Access to services)	
•	Capitalism (rise of funeral industry) Consumerism	X
	Social media	
	Home funerals	
	Death doulas	
•	Baby boomers	X
	Grief counseling	
•	Modern family (transient children, empty nesters, etc.)	X
	Immigration (cultural melting pot)	
•	Death phobia/ fear / anxiety	X
	Discussing death (death café, the groundswell project, death over dinner)	
•	Personalization	X
•	Personal development	
Ta alaa ala	1	
Technolo		
	Genetic sequencing (predictive/preventative) Artificial Intelligence	
	Augmented Reality	
	Smart homes	
	3D printing	
	Nano tech	
	Sensors	
	Wearable's	
	Robotics	
	tech afterlife immortality (living on in digital realm)	
Environn	ental Climate change/global warming	X
•	Traditional burial	А
	Cremation	
	Cremation alternatives	
	Sustainability	
	Sustainable burial practice (green space, composting bodies, Alkaline	
hyd	rolysis)	
	Naturopathic medicine	
•	Cityscape design – building retirement cities, rethink transport, access	
Economic		
	Medical tourism	
	Rise of palliative care	
	Retirement homes	
•	Bankruptcy at/by death	X
	Scalability of service (funding concerns)	
	Entrepreneurship	
	Death trade	
	Capitalism	
Political	Dhamisian assisted Darit	<u></u>
•	Physician-assisted Death	X
	Public health reframing medicine – away from focus of 'curing'	v
	institutionalization of systems (cure focused)	X
Values		
varues	Spiritual poverty (secularization)	X
	Dignity at death	
	Advanced care planning (planning decisions around death in advance, also	
crea	ting memories for loved ones)	
	YOLO (secular perspective, lifestyle choices)	
	Prolonging life	X
	Celebrating death (Guy LaLiberte)	

The horizon scan and expert interviews served a critical role to uncover a series of key drivers that are predominant forces in the current shifts underway in our Canadian culture around death.

Key Drivers

A list of key drivers was revealed in the horizon scan that created a powerful image of the current cultural context of death management.

- Debt row: Dying and funeral decisions occurring based on financial means and options, often leading to bankruptcy.
- Capitalism of death: The enterprise of funeral and burial services, beginning after the American Civil War and relatively unchanged to present.
- The Baby Boomer bulge: The significantly large demographic born post WWII between 1945 and 1964, now in their golden years creating a unique volume of pressures on the Canadian healthcare system.
- Death phobic culture: The broadly engrained fear to both one's own mortality and of those who are deceased.

- **Personalization of death**: The desire to make mindful decisions about one's death experience and burial decisions.
- Sustainability and carbon footprint of death: Interest and demand in more sustainable and green burial practices.
- Physician Assisted Death: The recent Supreme Court Decision (February 2015) to decriminalize assisted death in the Canadian Criminal Code and allow Canadian adults in grievous, unending pain have a right to end their life with a medical aid.
- Spiritual poverty of death rituals: Redefining the religious traditions of funeral rites to commemorate and celebrate the dead in modern and meaningful contexts.
- **The Good death**: To be mentally at peace with death and die without gratuitous pain and suffering.
- Medicalization and institutionalization of death: Shift of death from the household to the hospital beginning post WWII

and continuing to be a central role in the medical system in 2015.

- Prolonging life: Technology leaders like Google Calico who are leading the big data exploration of human genealogy and disease to find solutions to prolong and experience healthier lives.
- Transition in family structures:
 Change in the dynamics of work and travel that leave fewer at home and available to care for a dying loved one.

This diverse list of forces each has a compelling role to play in the transition of cultural views on death. Over the last century, it would seem that we have been very slow to innovate in the domain of death. Considering Canada's short existence in history, we do not have a rich, deeply rooted culture around death. What is most apparent from the analysis is that we have assembled a variety of collective perspectives that symbolize our view of death. These key drivers are connected to the deeply fortified cultural outlook, but exist at a higher surface level where we can observe them. CLA helped to visualize the cultural shifts that might be possible over a one to two decade period. Within the layers there are

distinct and predominant relationships revealed. Moving from myth to litany, the analysis provides a series of insights as to how the futures of dying in Canada may come to take shape (Figure 5).

The analysis revealed intricate connections within the key drivers and themes of the expert interviews. The key findings are listed below.

Key Findings

i. Death phobia will be challenged the Baby Boomer bulge and our need to address their wants and desires.

The metaphoric significance of death phobia has a direct correlation to the litany of concern with the Baby Boomer bulge currently at play.

Through the worldview that Canadians have developed of a 'Good Death', the structures and systems have been put in place to address the needs of dying peacefully and with pain management.

ii. Family traditions and the changing structure of families will promote the entry of new services such as death doulas.

The archetypal nature of family customs and conventions has a heavily important

*	A STATE OF S			
S Green Burials	Cremation	Carbon Footprint of Death	Sustainability	
y Finding Debt Row	Capitalism of Death	Personalization of Death	Prolonging Life and Control of Ageing and Dying	
al Layered Analysis - Key Findings Home Death/Advance Care Debt Row ge Death Doulas Planning	Physician Assisted Death	The Good Death	Fear of Death	
ayered Ama Home Death/ Death Doulas	Transition in Family Structures	Spiritual Poverty of Death Rituals	Entrenched Family Traditions	ths
S 6 2	Problem Medicalization and Institutionalization of Death	The Good Death	Worldview Death Phobic Culture	Metaphors & Myths
Litany				Myth

Figure 5 – Casual Layered Analysis key findings

role in our cultural perceptions. As there has been a transition in family structures and dynamics from the traditional nuclear family, there has also been a distinct shift toward a more secular society. These building blocks are creating new opportunities for services that can handle the desires of the contemporary individuals' last wishes, within or outside of tradition, such as death doulas.

iii. The deeply seeded fear of death will begin to unwind as advanced care planning becomes more normalized and common.

The fears associated with dying that have shifted our culture to drastically disengage from the discussion of death will see positive movement as a result of the physician-assisted dying policy, building from the desire to experience a good death. These shifts in dialogue will also propel more Canadians to seek and create advance care plans in order to ensure that their wishes are observed in their end-of-life.

iv. Our preference to exercise control over discussing death and generally eluding it as long as possible will shift as the ageing population begins to outlive their

retirement savings and desire personalized care.

Within our western capitalist logic, the desire to prolong life has begun to be realized in an enterprise format as companies seek to 'disrupt' the natural lifespan of humans. Connected to this image is the desire to personalize the death experience and subsequent funeral celebration and create new approaches to the rituals. These consumer-driven preferences are currently becoming available to those who can afford it. As the Baby Boomer bulge continues to age, the question of the fees associated with dying will create tensions resulting in transition of the marketplace to include more diversity of options and fee ranges.

v. The ongoing dialogue of concern for sustainable solutions to a planet suffering from the impact of climate change will lead to more environmental consciousness in burial practices.

As new players are already entering the market to provide eco-friendly alternatives, the traditions of burial and cremation are being assessed for their negative legacy on the surroundings. As more awareness is created about the

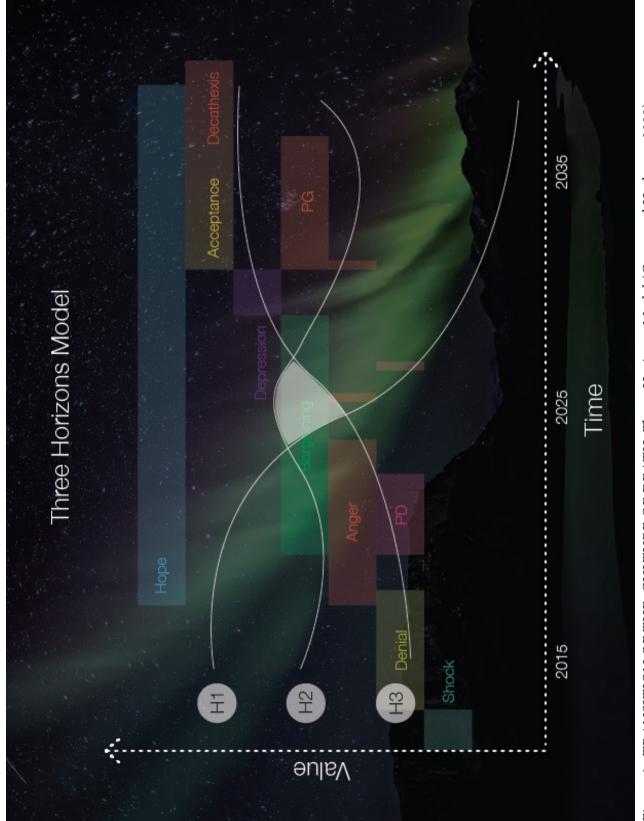


Figure 6 - TRANSITION OF THE CULTURE OF DEATH, Three Horizons Model (Curry and Hodgson, 2008)

Figure 6 - TRANSITION OF THE CULTURE OF DEATH

Horizon 1 (H1) "Death Phobic Persistence"

Horizon 2 (H2) "Negotiation of Unmet Needs in Death Management"

Horizon 3 (H3) "Reintegration of Death in Life"

carbon footprint of funeral rituals, a transformation will occur in the burial and funeral mass marketplace.

Three Horizons Extrapolation

A very clear and distinct direction was shaped from the previous analysis. Implications of changes already underway in green burial and holistic, de-institutionalized healthcare options such as death doulas, began to form a perception of a preferred future ahead. One strong vision of the future was articulated by using the threehorizons model for scenario planning. This framework is a vision building exercise that incorporates data into the present future (Horizon 1) and connects to the desired future (Horizon 3) by understanding the barriers at play (Horizon 2). With two axis's representing value and time, the three horizons are depicted as a visual means to understand the complexities of the

relationships and the changes involved in moving beyond the death phobia in contemporary Canada, over the next 10-20 years.

As noted by Curry and Hodgson (2008), the three horizons each serve a distinct purpose in visioning the future. The first horizon (H1) is "the current prevailing system as it continues into the future, which loses "fit" over time as its external environment changes" (Curry and Hodgson, 2008, pg2). The first horizon for this research purpose can be characterized as the "Death Phobia Persistence". Building over the last millennium, both Aries and Illich indicated that the transition of death into a medicalized and institutionalized setting has unintentionally created, what many of the experts interviewed including Stephen Jenkinson describe as, a 'death phobic culture'. As Dr. BJ Miller, Palliative Care Physician and Executive Director of Zen Hospice in California shared, "From a population point of view, from a citizen point of view, the common themes are the decay of traditional family structures. We have become a more secular society. As a secular society, you don't inherit a batch of rituals that ease the angst". While Atul Gawande more recently reiterates our challenges with our

current healthcare philosophy of ageing, death and dying, Elisabeth Kübler-Ross noted many decades before that death has become a dreaded idea in the ways in which we think about life. Envisioning an enhanced 8th stage of O'Gorman's model, the 'Death Phobic Persistence' is not sustainable in the face of reconciling our understanding of death and addressing the current challenges of Baby Boomer demands, while also creating space for new services such as physician-assisted death. The cultural context will need to shift in order to embrace a renewed perspective on death as a stage of life.

The third horizon (H₃) argues "about the future of the system which are, at best, marginal in the present, but which over time may have the potential to displace the world of the first horizon, because they represent a more effective response to the changes in the external environment." (Curry and Hodgson, 2008, pg2). In this application, the third horizon would be characterized as the "Reintegration of Death in Life". This image of the future would seek to envision a radical shift of culture around death and dying, to welcome it into common dialogue, life and family planning experiences, and general social acceptance. This scenario would seek to

provide fertile ground for innovations in death services and encourage new and widely embraced traditions in funeral rites and celebrations. The cultural perspective of death would shift into a more notable connection to our environmental impact and would unwind our propensity for extending life at all costs to the quality of life. Reclaiming past traditions, dying would be more pervasive in home settings and community support would be in place to address the needs of family and loved ones, as well as well as the person who is transitioning into their final stage of the life cycle. As Kathi Kelly, a Death Doula and Chaplin noted in her interview, "Death doula is not new. It's very old. A revisiting of what has been around the world. But there are more tools of the trade". Healthcare would become a more truly holistic practice with the front lines of primary care infused with readiness to lead discussions about death with patients and direct them to an increased array of options beyond treatment.

In order to shift away from the current systems of "Death Phobia Persistence" into the preferred "Reintegration of Death in Life", the second horizon must serve to bridge the barriers and challenges that will arise from such a cultural shift. The second horizon is defined as "an intermediate space in which the first and third horizons collide. This is a space of transition, which is typically unstable. It is characterized by clashes of values in which competing alternative paths to the future are proposed by actors." (Curry and Hodgson, 2008, pg3). This collide will create a bridge between H1 and H3 and experience a cross of a chasm of visionaries' beliefs and the status quo of death management. The profound differences in beliefs from the current state to the future, more desirable state of the culture around death will be experienced in this phase. Crossing the chasm theory (Moore, 1991) (Figure 6) builds on Everett Rogers' theory of *Diffusion of Innovations* (1995) and is premised in marketing disruptive technology to mainstream market. It can also be applied to the innovative businesses rising to disrupt the capitalist market of funeral and death services. In the second horizon the funeral industry, which has had almost a century without disruption, coupled with the patient/client values shifting to more sustainable practices will lead the charge for new products and services. Funerals will begin to become more radical and take place in more public settings beyond designated

spaces. Pop-up funerals and memorials where even strangers can offer their support and participation in honoring a life. Broader public sustainability concerns will guide new demand for green burial options. Human composting will arise as a new wave of interest in committing to protecting the planet from climate change beyond our human life, and leaving the legacy of low environment impact in our death. A cultural preference for a 'good death', might lead to include a 'good conscious burial' as well. The 'good death' will take shape in meeting enlightened consumers' demands for dying in a place of the most comfort, with the people you most love, in a way that is pain managed and not necessarily treatment focused. This will mean a culture of emotional acceptance will build, to allow for dialogue to connect people to their own death experience. The 'good death' will become a goal for individual Canadians on a mass scale, who will recognize that quality over quantity can be a sacred gift. Home death will become a common mobile community service and families will actively participate in caring for the body of their deceased loved one. Baby boomers wanting to engage in meaningful dialogue and decision-making around their deaths will experience challenges

in this transitioning system that is not yet ready to support alternatives outside of the medical institution. These conversations and early market demands already visible in the first horizon are creating momentum to see Canadian society cross the chasm of new services in the next 10 to 20 years. Although we are currently holding position in the visionaries' stage of Moore's theory, the "Negotiation of Unmet Needs in Death Management" will characterize the second horizon. As Katrina Spade, Founder of the Urban Death Project noted in her interview, "Death and dying is a design decision. If you choose the status quo, you may not think you are designing your death, but you are." Returning to the CLA analysis, an example of unmet needs is demonstrated with the litany of people's desire to die in their homes. Currently, as many experts noted, we do not have a system in place to aid in home death. Many of the challenges not only stem from the missing investment in practitioners to handle death in the home as part of the healthcare system, but also in the dynamic shift of family structures. With families experiencing more transient lifestyles and society becoming increasingly secular, the community supports are not always in place to assist. Yet, many ageing and dying people hold strong beliefs

in family traditions. Death doulas have recently reappeared, following a resurgence of midwives for birth, to aid in home needs where families are unable to cope. As Silvan Luley of the not-for-profit Dignitas in Switzerland notes, "Our Western 'civilised' and 'modern' society has lost touch with the simple fact that life is a come-and-go and that death is just a normal thing and a part of life just as much as birth. Making a link to giving birth: whilst for many years it was recommend to women to give birth in clinics, there is now a bit of counter-movement, of women preparing and giving birth with a midwife at home, just like it was normal in the old days."

An S-curve of adoption will define the third horizon as the progression occurs from the previous horizons. In his book *Diffusion of Innovations* (1995), Rogers describes, "diffusion is a kind of social change, defined as the process by which alteration occurs in the structure and function of a social system" (Rogers, 1995 pg 6). When new ideas are created, social change occurs as a result. The S-curve can be seen in the third horizon, as current adoption is low and will build through the positive regard by tastemakers and opinion leaders. Physician-assisted death prescribing more widespread dialogue

and the pressures of the Baby Boomer surge of needs will have considerable influence over the transition. In the third horizon the innovations in death services will reach critical mass in adoption and become mainstream market prerogatives. The diffusion of innovative practices will become high, as the culture shifts across the present generations of Canada to become more engaged in death discussion, planning and services. The recognition of the need to take the learnings that we have already and implement to improve the system to meet the changing needs of an aging population. As BJ Miller, Executive Director, Zen Hospice Project and a Palliative Care Physician framed it, "We don't need a lot of innovation per se, and we need to exercise what we know. If we implemented everything that palliative care already knows we would be miles ahead. So much of the work is exercising what we know and activating it." The third horizon is the opportunity to embrace the knowledge that exists and implement services that will make sense holistically to provide a 'good death' for the benefit of people, planet and profit. A greater investment in palliative and hospice care will mature to be a more integrated into the healthcare system. The consumer acceptance and embracement of green deaths will become more normalized

and ignite new traditions for future families who seek to be buried in memorial forests instead of urban concrete graves. Death management will see a boom and bust of entrepreneurs who will build a market offering that closely resembles the newly acceptance of death in life, shifting away from shock, denial and anger, into an embracement of options to curate the end of life more openly and with more options. Historian William Strauss and Demographer Neil Howe's generational theory can be applied to the threehorizons as a means to understand the possibilities of change from the first to third horizon, or 20 years. In their book *The Fourth Turning* (1997) Strauss and Howe created a framework (Table 4) to understand American generational biographies. The theory defines a generation as born over a span of roughly 20 years and or the length or one phase of life, which they define as childhood, young adulthood, midlife and old age. Each generation rather than sharing just an age bracket also share an age location in history, common beliefs and behaviors, and perceived membership in that generation (Life Course Associates). In the case of Baby Boomers this would be characterized as a group who identifies as born in the decades post-WWII. With the edges of the Baby Boomber generation reaching

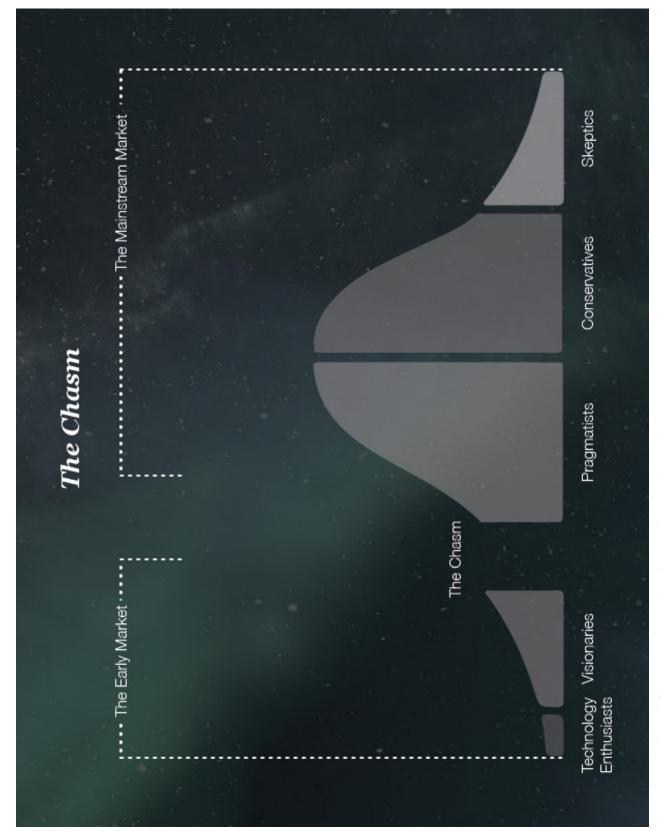


Figure 7 - Adapted from Crossing the Chasm Theory (Moore)

the age of 65 in 2015, the horizons will mean that these distinct tastemakers will be a driving force over the next 10-20 years in evolving death management to reflect the unique desires of this generation. But the Baby Boomers will not live in isolation of other generations and will in fact need the support of the younger generations to transform the systems at play. Becker's concept of our innate drive to "heroics" that creates our culture can be identified throughout each of Strauss & Howes' four generational archetypes, leading the 'Nomad' and 'Hero' generations to become invested in their parents and grandparents care, as they come to terms with their own understanding of death in the second horizon. The changing myth of death phobia will alter as the litany of the Baby Boomer bulge create demands for new ways of dealing with end-of life and revolt against the causes of institutionalization as the primary method to deal with end-oflife populations. As seen in a historic framing of generational relations, the Baby Boomers will also be influenced by their own parent's experiences with endof-life care. As Dr. Jeff Myers, Head of Palliative Care at Sunnybrook Hospital shared, "An interesting dynamic are baby boomers wanting to participate in their care in a more mindful way than

their parents". The tastemaker group is in a unique position to create change in the coming years. An outline of Strauss and Howe's distinct archetypes, reflecting the current populations can be reviewed in Table 4.

Through the discerning of fourth turning theory, we are able to understand the cycle of shifting populations that will characterize the next 10-20 years. With a deeper understanding of the prevailing generations incorporated into the three horizons framework, it becomes apparent that the nature of our cultural values of the end-of-life need to be critically assessed. If we can recognize and discuss our current horizon of death phobia, we can see how the important transitions can begin to take shape and create a more sustainable cultural fit around death in contemporary Canada. There is already a change of meaning at play that is seeking to address needs, fears, and desires. If we choose to lean in and observe the shifting ground, we will collectively be on track to uncover the potential of reversing our current cultural approach to death and revive a much healthier perspective of inclusiveness. As Stephen Jenkinson, Author and Spiritual Activist and teacher noted in his interview, we "make a revolution by democratizing

wisdom and knowledge. That means that a death phobic cultures principle responsibility is to learn dying, not what to do about dying".

The third horizon would bring inclusiveness of death. It would be a place for even children to participate in the departure of their loved ones. Whereas our current landscape removes young, malleable minds from the darkness of death, it might be possible in the future to see an intergenerational cultural value of experiencing death. As Linda Hochstetler, a social worker specializing in death and dying shared in her interview, "Culturally we need to go to a larger intergenerational involvement of dying and death. We need to involved little kids in the process. In Canada we don't do this and it is traumatizing for kids not to see death. It can become so much more generally accepted and have more personal experience with it". The third horizon will be a future where the traditions of death rituals expand to allow for more options and personal expression. Linda also noted that, "If you look at weddings and how they were prescribed and now what they are. It's this generation that will change it". In fact we are already seeing pockets of the future in green

burials and the inclusion of physicianassisted death. These are steps toward a reinterpretation of the cultural meaning of death. Participation and demand from the 'Nomads' or Gen X and the 'Heroes' or Millenials as we commonly call them, will be a key to determining success. In 20 years time Gen X will move into the position that Baby Boomers are currently in. Looking back to Kübler-Ross' stages of dying, the third horizon will experience the minimization of much of the first few stages in this cultural evolution. Denial will become an antiquated practice, recognized as a meaningless approach to death. The anger that becomes negotiated in the second horizon will also become an obsolete emotion to the death of an aging person. Instead, the acceptance of the life cycle will increase and steady the cultural relationship with death. Aging individuals will endure a sense a hope across the stages, as they approach death and accept it. This hope will be a sense of appreciation to have lived life, and be offered the opportunity to embrace a 'good death', of their choosing either assisted or not. The fear and denial of death replaced with an inherent sense of understanding that life is a cycle beyond our control. The "death" of death phobic culture will leave us with

hope and acceptance. The trends that are pushing us toward a third horizon, notably physician-assisted death and the Baby Boomer bulge are already becoming visible in the first horizon. The demographic shifts and legislation changes will create broader strokes of change in the coming decades to reveal the future state of a 'good death'. The momentum already underway to challenge the institutionalization of death will stimulate meaningful discussion of dying in the home and

drive the necessary change for inclusion of services to provide this transitioned approach. For these critical transitions to take place, we must open our eyes to the current death phobic culture and recognize that change is possible and desirable. These pockets of a future state of the reintegration of death into life are already visible and will become even more stimulated by the increase in visibility of the trends and drivers noted.

Prophets –	Nomad –	Hero's –	Artists –
Baby Boomers	Gen x	Millennials	Children
(born 1943 – 1960)	(born 1961 – 1981)	(born 1982 – 2004)	(born 2005 – present)
Prophet generations are born after a great war or other crisis, during a time of rejuvenated commu- nity life and consen- sus around a new societal order. Their principle endow- ments are often in the domain of vision, values, and religion.	Nomad generations are born during a spiritual awakening, a time of social ideals and spiritual agendas when youth-fired attacks break out against the established institutional order. Their principle endowments are often in the domain of liberty, survival, and honor.	Hero generations are born after a spiritual awakening, during a time of individual pragmatism, self-reliance, laissez faire, and national (or sectional or ethnic) chauvinism. Their principle endowments are often in the domain of community, affluence, and technology.	Artist generations are born during a great war or other historical crisis, a time when great worldly perils boil off the complexity of life and public consensus, aggressive institutions, and personal sacrifice prevail. Their principle endowments are often in the domain of pluralism, expertise and due process.

Table 4 – Adapted from Generational Archetypes of the Fourth Turning (Strauss and Howe, 1997) Life Course Associates



Chapter Four Conclusion

"The fear of death follows from the fear of life. A man who lives fully is prepared to die at any time." - Mark Twain

Conclusion

THERE IS AN IMMINENT SHIFT IN THINKING happening in contemporary Canada regarding cultural views on death and dying. As technology continues to galvanize medical territory and give hope to an endless lifespan, we are turning our back on death as part of the cycle of life. This research exploration focused on the shifting ground of the culture of death and dying in Canada, including innovative services and the generational context that is changing our collective perspective and entrenched culture. Research engaged current experts from a variety of fields within the domain of death management, and sourced perspectives from a variety of relevant theoretical and historical frameworks to provide insights into contemporary views. The investigation revealed that Canadians are in a distinct period of opportunity to recognize how needs of the dying and their loved ones can be met and made more desirable beyond our current practices. We are experiencing a transition of our shared western perspective of repressed values of death. According to historian Phillipe

Aries (1974), western attitudes have developed from a number of shifts over the last millennium in the views of end-of-life. Transition from previous centuries where death was connected to both religion and nature with strong presence in the community, to today's more familiar propensity of hiding away from the weight of death and preferring the process to be handled by medical experts. Recognition of the current death phobic culture is at the cusp of modern discussion on dying as we experience the beginnings of a cultural shift away from 'Death Phobic Persistence' into a more desirable and holistic return to the 'Reintegration of Death in Life'. Anthropologist Ernest Becker proposed that our present "Denial of Death" (1997) has been developed and reinforced by the very culture we have created. It drives us to 'heroics'; Instead of pondering our place in the universe and worrying about our ultimate life-purpose, the fear of the end-of-life drives us to create meaning in our life.

Canada's current healthcare system aids

the dying with an institutionalization approach. Final days of one's life are commonly spent fighting against the end-of-life, or managing the pain of transition into death. Philosopher and priest Ivan Illich (1977) challenges this approach in claiming that our system of medicalization was a "threat" to our collective health. By transferring the practice of death to an institutionalized system we are potentially harming ourselves by enticing life long patients, instead of making autonomous decisions and living healthy lives. In fact, Illich is not alone. Aspects of Atule Gawande's perspective as a medical doctor speak to concerns of the relationship of medicine with ageing and dying. Gawande conveys how a highly medicalized western approach brings many potential faults and failures to patients, while people fight for more life instead of living and potentially enjoying their final days. The data elicited for this research revealed distinct notions of the shifts underway. The analysis of expert input shows evidence that we are experiencing an enhanced period of Stella O'Gorman's (1998) 8th stage in the stages in development of current attitudes toward death. Building on Illich and Sweeting & Gilhooley's suggested previous stages (Figure 2), O'Gorman's' model

proposes a distinct loss of rituals in modern times associated with death and dying. She acknowledges that this is result of the professionalization around death management. At an interesting and timely intersection are the bulges in service demands for an ageing Baby Boomer population and the landmark decision to decriminalize physician-assisted death. These events are subsequently on the leading edge of transforming the dialogue around medical 'care' for the end-of life and urging a re-evaluation of our culturally engrained notions of death management. In the fourth turning theory, Strauss & Howe (1997) note patterns of a recurring generational cycle. This cycle currently places the 'Prophet' or Baby Boomer generation, known for taste making, to lead the charge on dialogue and demand for their end-of-life decisions. The shifting populations that will characterize the next 10-20 years will observe Baby Boomers in the epicenter of the debates while supported by the younger generations, both Gen X (or 'Nomads') and Millennials (or 'Heroes') in the quest to reexamine views of death. The experts interviewed cited many indicators of a prevalent desire to 'return to holistic concepts', and evidence shows that shifts are underway toward building

a broadly authorized return to the perspective of death as 'right of passage'. A number of key drivers provide evidence of this evolution of thinking including an increased value and public interest in green burial techniques and a growing demand to invest in palliative and hospice care programs. A growth of public awareness and government recognition of the merits of advanced care planning reveal an emergence of necessary discussion of end-of-life mindset. Recognition of death phobia as a cultural norm provides a unique opportunity to surrender our images of the 'status quo' of death and reinvent entrenched traditions. An exploration with the causal layered analysis method created acknowledgement of the relationship between deeply see cultural views and the current trends and drivers that are visible in our current perspective. The increased awareness of challenges with institutionalization of death, where dying individuals are effectively removed from mainstream society, is experiencing tension as notions of a 'good death' are being reexamined. Questions of the purpose of pain management, the preference of location of care and the level of professional assistance in death, are all a part of this dialogue.

Although no one truly knows what lies beyond the end-of-life, it would seem that our commonly held relationship with denial and fear is stunting our opportunity to explore how services and innovations can create more desirable options. New services are already rising and offer enhanced death rituals. This is a strong signal that an upheaval of death traditions is occurring. We can already see a transformation in the traditional sorrow-filled, religious funeral to many opting for a celebrationof-life, in a secular space and inclusive of joy and laughter. Death doulas are breaking into the marketplace to aid home death, where the dying person often prefers to be in their final days and moments. Arrays of innovative burial techniques are pushing toward the ability to offer methods that put family and loved ones in the authority of caring for bodies of deceased. Innovations in science are creating greener burial options, proposing body composting as a means to safely return a body to earth without the impacts of chemicals and use of precious natural resources. Although these changes are underway, they remain currently in the fringe. The true momentum of transformation is ahead of us. Understanding the changes proceeding through the three horizons framework provide latitude

of understanding what will be required in the 'Negotiation of Unmet Needs in Death'. Transition from the current state through a second horizon will likely connect to the journey of grief as described by Elisabeth Kübler-Ross in the *five tages of dying* (Figure 1). To move beyond our current stage of 'denial' into the succeeding stages of Kubler-Ross's model of grief will be imperative to successfully attain value in and acceptance of death. It is possible that a period of public resistance and 'anger' might arise from the changes and innovations in death services, where traditions are reconstructed such as in the case of the access to physician-assisted death. The power of the 'bargaining' period might feature the negotiation of new practices and their effectiveness to meet the unmet needs of patients and community. Ultimately, we will arrive at a stage of 'acceptance', where the dynamic of dying in society will include intergenerational participation and death will be more openly and easily discussed. There is indication of this on a national scale with physician-assisted dying policies in development, and consultations with the public happening across the country. This new, emerging and yet retrograde paradigm of closeness with death will be a return to historical attitudes of death

to which western society has become polarized. Although this might be a long transition over decades before it is completely mainstream, the shifts that are likely to take place in the next 10-20 years will be critical to embracing an improved culture of death and dying. Many of the ways we 'used to do things' might return to consideration as we reflect on how our ancestors handled death.

Next Steps

To further explore the culture of death and dying in Canada, additional stages of research could compliment this exploration. This foundation of research evidence could serve to be enhanced by the integration of individual experiences navigating the radical shifts in the culture of death in Canada. Research could be carried out with people experiencing death over the next 20 years to inform and measure the changes outlined in this cultural exploration. The monitoring of the expansion of death services, as well as the evolution of cultural approach from a phobia and fear of death into the proposed reintegration of death into life, could be observed through participant research.

Supplementary research is recommended to more deeply examine the current healthcare system in order to understand what gratuitous suffering might exist for end-of-life patients. If there were failures in the system itself that could be indicating further changes to the culture, an extension of this research would provide further indication that change of culture is

necessary. In addition, an investigation into the religious beliefs and affiliations of Canadians would offer incremental value in understanding the cultural views on death and funeral practices. The premise of secular systems might come to be less relevant as immigration rises and new Canadians bring forth their cultural practices from other countries. Consideration could be given to conduct a Delphi survey in order to further compare and contrast the perspectives provided by the Experts. A Delphi survey would have potential to further support or expand on the findings of this research by narrowing the perceived values and issues of Canadians. Further study consideration could also be given to a fusion of the fourth turning and panarchy adaptive cycle as the evolution of systems come to reorganize around the Baby Boomer population decline over the next 10-20 years.

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