

**Death Becomes Them: Death Doulas, Gender, and Advance Care Planning**

by © Alana Tumber

A Thesis submitted to the School of Graduate Studies in partial fulfillment of the  
requirements for the degree of

**Master of Gender Studies Department of Gender Studies**

Memorial University of Newfoundland

**August 2020**

**St. John's Newfoundland and Labrador**

## **ABSTRACT**

In Canada, non-medical professionals called “death doulas” have emerged to address perceived gaps in current models of end-of-life and funeral care by providing services that allow individuals to “reclaim” their relationship with death, by educating and supporting clients and their families about their end-of-life options concerning palliative care and funerary options. In order to understand the role of the death doula, I interviewed six death doulas from across Canada. Using a feminist phenomenological approach I explored the following questions: How do death doulas fit into a larger project of death reform? How might hegemonic beliefs about death, gender, and social privilege complicate any roles they might have in death reform movements? Relatedly, in what ways do death doulas resist or reinforce the commodification of care-work? Their responses provided a glimpse into larger debates within the death doula community regarding regulation, the validity of training programs, commodification of care, the role of the death positive movement, and the importance of education.

Keywords: death doula, care-work, phenomenology, gender, death positivity, palliative care, advance care planning.

## **GENERAL SUMMARY**

This thesis is a qualitative, exploratory study investigating the role of death doulas in Canada in order to better understand how death doulas fit into end-of-life care and healthcare systems broadly. While the Canadian public knows relatively little about them, death doulas are identified as non-medical professionals who may be able to help patients at the end of life navigate health care and funeral systems. With this study, I set out to learn more about death doulas beyond this general understanding. Thus, I interviewed six death doulas from across Canada to answer the following questions: How do death doulas fit into a larger project of death reform? How might hegemonic beliefs about death, gender, and social privilege complicate any roles they might have in death reform movements? Relatedly, in what ways do death doulas resist or reinforce the commodification of care-work?

## ACKNOWLEDGMENTS

This thesis draws on research supported by the Social Sciences and Humanities Research Council. This research is also indebted to the support from the Aging Research Centre of Newfoundland and Labrador.

First and foremost, I want to thank the six death doulas who agreed to participate in this study. Thank you for taking time out of your day to sit down for an interview with me, and thank you for sharing your experiences and insights. I also want to take this moment to thank the Home Hospice Association for agreeing to advertise this study on their social media accounts.

The completion of this thesis would not have been possible without the input from my wonderful and endlessly patient academic co-supervisors, Dr. Carol Lynne D’Arcangelis and Dr. Sonja Boon of the Department of Gender Studies. Their support, insight, and endless encouragement kept me on task even in the moments when I wanted nothing more than to abandon this thesis. Thank you for your assistance and mentorship throughout my graduate school experience.

Lastly, I am nothing without my support system. This has been a challenging year and I am grateful for the support and encouragement from my family and also from my dear friend Simi Khosa. In particular, I want to thank my mother, Catherine Tumber. Your experience as a nurse was invaluable and you offered me perspectives I had not even considered.

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## **CHAPTER ONE: CONTEXT, LITERATURE REVIEW, DEFINITIONS, AND BACKGROUND**

This thesis is an investigation into the shifting landscape of death and dying in Ontario, Canada, namely in relation to death doulas' attempts to provide community-based palliative care. More specifically, in this qualitative study, I examine the role and social impact of death doulas in that landscape through the lens of intersectional feminist theory and feminist phenomenology and in-depth interviews with six death doulas. I investigate the following interrelated questions: How do death doulas fit into a larger project of death reform? How might hegemonic beliefs about death, gender, and social privilege complicate any roles they might have in death reform movements? Relatedly, in what ways do death doulas resist or reinforce the commodification of care-work?

Death doulas, also known as death midwives and end-of-life guides, are non-medical workers who provide services that include physical, emotional, logistical, and sometimes spiritual support in end-of-life care. Death doulas provide services that allow individuals to reclaim their relationship with death, often by assisting the dying person and their loved ones through the grieving process, by helping organize one's affairs before death and by providing information about funeral planning. Though the intents and goals of death doulas vary from individual to individual, the overarching goal of death doula work is to provide a "hands-on" approach to death and dying. This is done in order to strive for a 'good death,' described as "a death that is free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Institute of Medicine, 1997, p. 24).



Generally speaking, the six death doulas who participated in this study appear to agree with these characterizations of death doula work; however there was some disagreement regarding the scope of practice of their work. The findings from this study indicate a presence of multiple overlapping movements seeking “death reform” in North America, for the purposes of this study, “death reform movements” will be used as the umbrella term to categorize the movements seeking reengagement with death in North America. Broadly, these movements are as follows: the alternate death movement, the death doula movement, the community death care movement, and the death positive movement. First, the alternative death movement is described as “a movement with two main parts: The ‘green burial’ option, which involves no embalming and burial in a biodegradable casket or shroud, and home funerals” (Warfield, 2016, para. 4). Second, the death doula movement does not have central organization, however the participants indicated that the death doula movement seeks to see paradigm shift in the way that death is engaged with broadly, they believe death doulas can advocate for and help their clients prepare for the end of life. Next, the community death care movement seeks to see families “reclaim” a participatory relationship with death in Canada (Community Deathcare Canada, n.d.). Lastly, the death positive movement is perhaps the most popular movement associated with death reform. Popularized by author and mortician Caitlin Doughty, the death positive movement seeks to remove death’s status as a taboo topic by encouraging open discussion about death and dying (The Order of the Good Death, n.d.).

In popular media, death doulas are most often thought of as “allies” or “members” of the death positive movement (Leland 2018; Sismondo 2019; Booth 2019). For instance, in Sismondo’s (2018) interview with Toronto based “death worker” Kayla Moryoussef, she claimed that the majority of death doulas, like her interviewee Moryoussef, are participants in the death

positive movement (para. 4). However, many of the participants in this study stated that they do not want to be associated with death positivity, suggesting that there is more nuance to the death positive movement than meets the eye.

It is important to note that involvement in the death reform movements is highly individualized. While many of the participants in this study distanced themselves from death positivity and allied themselves with movements that are not explicitly death positive, that is not necessarily true of every death doula. There is the possibility that another death doula may identify as a member of the death positive movement while also participating in a smaller scale death reform movement. Since the death positive movement is the largest, most popular, and most well known of the death reform movements, there is understandably much overlap with smaller death reform movements. However, while many of these movements may be categorized as “death positive” it is important to understand not every member of smaller death reform movements wants to be associated with death positivity. For more information, please refer to the upcoming section “The Death Positive Movement” which provides an in depth overview of the death positive movement.

### **What is a Death Doula?**

American anthropologist Dana Raphael coined the term “doula”<sup>1</sup> in 1973 to describe the role of non-medical care-workers who provided postpartum support to women. Since 1973, the term “doula” has expanded beyond obstetrics to include delirium doulas (Balas, Gale, and Kagan, 2004), abortion doulas (Chor, Lyman, & Gilliam, 2016), illness doulas (Robinson, Spencer, & Lewis, 2017), and disability doulas (McGarry, Stenfert Kroese, & Cox, 2016). Birth

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<sup>1</sup> Doula derives from the Greek word “doule” meaning “female servant” or a “woman who serves” (Mirriam Webster Dictionary).

doulas, arguably the most well known type of doula, can have community-based doula practices and operate within hospital settings. They are also known for addressing inequities of care for incarcerated or previously incarcerated women (McLemore & Warner Hand, 2017; Shlafer, Hellerstedt, Secor-Turner, Gerrity, & Baker, 2015), and for those in lower socio-economic classes (Kozhimannil, Vogelsang, Hardeman, & Prasad, 2016).

Death doulas, similarly, are non-medical care-workers who “support the dying person and their family throughout the dying process and often beyond” (Arnup, 2018, p. 40). While death doula is the most common title used, some end-of-life non-medical care-workers prefer other titles including end-of-life doula, thanadoula, death midwife, or end-of-life guide. For the purposes of this study, I refer to individuals who provide non-medical care-work to dying individuals and their loved ones under the general umbrella term “death doulas.” While the services provided by death doulas vary from person to person, death doula services typically include advance care planning, bedside attendance, bathing and dressing the body, providing home funeral services, burial rituals, and grief support (Arnup, 2018, p. 40). While Arnup attributes the role of “bathing and dressing” the body to death doulas, it should be noted that in Ontario, British Columbia and Saskatchewan it is illegal for everyone except for registered funeral workers to bathe and dress the body in exchange for money. Moreover, although there are many certification programs offered throughout Canada to train individuals as death doulas, they are not regulated under the Health Professional Act in Ontario (1991) nor are they regulated under British Columbia’s Health Professionals Act (1996) or Saskatchewan’s Medical Professionals Act (1986).<sup>2</sup>

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<sup>2</sup> For this thesis, I focus on Ontario, British Columbia and Saskatchewan’s legislation since these are the provinces the participants currently reside in. Please refer to your provincial or territorial health professionals act in order to determine whether death doulas are regulated in your location.

Birth doulas, illness doulas, delirium doulas, disability doulas and death doulas have one aspect in common: they aim to address perceived gaps in current models of care. For instance, the role of an illness doula is to provide companionship and emotional and informational support for the patient as they navigate the health care system so that there is less pressure on family who may not be available (Robinson, Spencer & Lewis., 2017). As a support to both the patient and their loved ones, death doulas may be crucial in helping create an environment that is more conducive to emotional healing in the wake of a death (Bales, Gale, and Kagan, 2004, p. 41). These examples illuminate the ways death doulas currently fit into healthcare practices to support not only the patient but also those who care for them. To understand fully the perceived gaps in healthcare systems that doula models seek to address, it is important to examine societal attitudes towards death and dying.

In the Economist Intelligence Unit's report on "The Quality of Death," researchers found that the "medicalization of death in Canada has engendered a culture where many people are afraid to raise the topic of death" (2010, p. 20). The cultural fear of death, alternatively known as "death denial," can contribute to poor experiences with medicalized death that then can transfer into a costly funeral culture. The result is an "acute use" of hospitalization at the end of life (Arnup, 2018). To this, Cassandra Yonder, a death doula, and founder and instructor at "BEyond Yonder Virtual School for Community Death-Caring<sup>3</sup>," wants individuals to "encourage cultural reengagement with community centred dying, death care and grief" (n.d., para. 2) in order to assist families in supporting their dying at home and develop frameworks that contribute to ecologically sustainable funeral systems. Yonder's statement suggests that many death doulas seek to facilitate conversations about the end of life early so that patients may more easily obtain

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<sup>3</sup> Capitalization on BEyond is intentional.

services they desire or require. In fact, as I recount in my data analysis chapters, I found that many of the participants were in agreement with Yonder. On more than one occasion, Yonder was spoken of in reverence, suggesting that she is a key figure in death doula organizing in Canada. Two participants in particular were in agreement that death doulas should be able provide both end-of-life care and post-death support, a statement that suggests there is controversy surrounding the perceived legitimacy of death doula services particularly after a death has occurred. Other participants, however, aligned death doulas with primarily preparatory roles, but nevertheless stressed that families have the right to care for their own dead if they so desire.

Death doulas are primarily women-identified and part of a larger trend of women entering the death industry: for example, in 2018, an estimated 70-80% of those enrolled in mortuary school identified as women (Floody, 2018, para. 1). In terms of death care and end-of-life planning, women-identified individuals do the majority of paid and unpaid care-work, jobs that neoliberal societies tend to devalue. In this sense, death doulas can -- and should -- be understood within the context of care-work. As scholars take notice of women's involvement in mortuary sciences in particular, it is important to understand that the discourse of care often reduces women to archetypal motherly stereotypes. For example, in their article "SIX FEET UNDER: Why these women chose the world's saddest profession," Wylie (2016) uses a biological essentialist argument to elaborate on why women are entering mortuary school at unprecedented rates. Framed as naturally caring, the women of Wylie's article are martyrs to the grief of strangers. This framing is problematic for a variety of reasons, but most importantly because it collapses the work of women-identified death professionals under a singular factor: caring. The devaluation of care-work has historical roots, which include the professionalization

of mortuary work to campaigns against women who possessed specialized knowledge and skills in death, dying and care-work.

Currently, there appears to exist community misinformation or misunderstanding about the role of the death doula and further, no clear consensus on what services death doulas provide. Lack of regulation likely contributes to this lack of clarity; in the current context, each death doula is able to determine for themselves what services they will provide. The downside of this outcome is that describing death doula roles and responsibilities presents a challenge. For example, while I initially understood death doulas as assisting with pre-planning one's affairs for death (Gonzalez, 2019, para. 6), I did not understand the variety of services or nuances that this can entail. For example, Davie (2019) claims that death doulas provide emotional support to their clients (para. 2). Watson (2016), meanwhile, claims that a death doula can teach their clients how to tend to a body post-death (para. 7). Notably, not every death doula will provide every one of these services. In fact, one of the main goals of this thesis is to gain a clearer view of what services death doulas commonly offer. As I discuss in Chapter 3, only two of the death doulas I interviewed provide respite care and bedside attendance; only one provides assistance to families post-death.

Outside of these more common services, Browne (2015) claims death doulas or midwives provide "counselling, forgiveness rituals, at-home funerals" as well as "end-of-life spiritual care for the secular" (para. 1). However, I would caution that "spiritual care for the secular" is an oxymoron that effectively frames non-Western spirituality as decoupled from sacred religious practices. This is problematic for a variety of reasons, but mainly because it presents non-Western religious practices as consumable, trendy, and meant predominantly for white populations. Browne's approach to the role of the death doula also raises questions around not

only how spirituality is conceptualized outside of religious institutions, but also around cultural appropriation. The photograph used on Browne's article for *Maclean's* magazine features Sarah Kerr, a white woman beating a drum over Rick Buck, a man diagnosed with terminal cancer, as he reclines with his eyes closed on a sofa. This representation of a death doula is a distinct departure from the more practical end-of-life preparations I had been envisioning. While clearly not every death doula is involved with the appropriation of Indigenous traditions, Browne's description of "spiritual care for the secular" elevates blatant cultural appropriation and another example in the pattern of white people claiming non-Western spiritual practices in an attempt to attain wellness or enlightenment. Questions of both spirituality and appropriation emerged during the course of my interviews, and I discuss these in more detail in Chapter 3.

Since there are a limited number of studies on death doulas, there is a gap in data about their role and effectiveness in health care systems. Of published studies, researchers such as Corporon (2011), Fukuzawa and Kondo (2017), and Lentz (2014) have focused on models for doula approaches to end-of-life care. Researchers such as Elliot (2011), Mitchell (2019), and Trzeciak-Kerr (2016) have studied the lived experiences of death doulas. However, previous studies lack an interrogation of Western constructions of knowledge and the bias of white male perspectives in medicine. On the surface, death doulas appear to support a palliative approach to end-of-life care that minimizes invasive medical intervention, allows the patient to stay at home, and prioritizes quality of life over longevity (World Health Organization, n.d., para. 2). Many death doulas, especially those involved with Community Death Care Canada (CDCC), strive for community based death care that is developed "organically" through grassroots organizing (Community Death Care Canada, n.d., para. 2). In that sense, their philosophies are alternative to contemporary models of end-of-life care. However, among my participants, there seems to be a

failure to account for experiences of death outside of a middle-class white perspective, perhaps because the majority of them appear to be of that demographic.

### **A Historical Overview of Eurocentric End-of-Life and Funeral Care**

The pre-industrialized history of death in the United States of America was of great interest to the participants in this study. In fact, this history frames how they conceptualize their practice, and influences their perceptions about how end-of-life care should operate today. For this reason, I provide an overview of Eurocentric death traditions in both Canada and the United States to better understand participant references to the history of end-of-life and funeral care.

As Sandwell (2016) argues, unlike Britain, Western Europe, and the United States, industrialization came late to Canada, but occurred rapidly during the mid-nineteenth century, often without adequate infrastructure to support growing urban populations (p. 4). Without proper sewage disposal systems, clean water sources, and sanitation, urban centres became prone to epidemics such as cholera, tuberculosis, smallpox, and typhoid fever among many other contagious diseases (Mercier & Boone, 2002, p. 420). Up until this time in Canadian history, death was most often tended to in the home. Moreover, prior to the professionalization of the funeral industry, which began during this rapid period of industrialization and became commonplace by the mid-twentieth century, death and funerary care most often fell to women. In short, the community-oriented death and funeral rituals prior to twentieth-century Canada indicate that death and mourning were public events. While death and the ways communities have historically tended to their dead ought not to be romanticised, as death is an occurrence that can be very painful, it is worth noting the historical differences to contemporary death and funeral care.



In *The History of American Funeral Directing*, Habenstein and Lamers (1955) describe how in the nineteenth century the home was seen as “a central point of mourning” (p. 15) and thus, death care can be seen as a form of emotional labour. Rundblad (1995) expands on this point to illustrate that nineteenth-century death care consisted of specialized knowledge that fell to what she terms as “shrouding women” -- women in communities who assisted loved ones in washing, dressing, shrouding, and presenting the corpse (p. 173). According to Rundblad, since death was viewed as an extension of providing care for the sick, tending to the body post death was assumed to be a woman’s responsibility (p. 175). Similarly, due to high infant mortality and maternal mortality rates, Rundblad argues that it would have been rare for women to grow up without witnessing death, since women were often in attendance and assisting laboring women during childbirth. The knowledge possessed by shrouding women enabled them to approach their roles as authority figures on the subject of preparing bodies for burial (p. 177). Shrouding women gained their skills through instructions passed down from mothers and grandmothers, and they honed their skills through hands-on practice in what Rundblad refers to as an “apprentice-like” training (p. 178). Rundblad’s work is of particular importance to this study, since the participants I interviewed spoke of “returning” to an idealised, almost romanticized form of death care that is similar to the work of the shrouding women that Rundblad describes.

As the funeral industry professionalized and embalming became popular in post-Civil War America, as Habenstein and Lamers (1996) explain, the Civil War was “the first conflict to see embalmers waiting and working in camps, on battlefields, in government hospitals, and in nearby railroad centers, to serve the needs of the military and the families of the fallen” (p. 212). By the end of the Civil War, embalming had become so widespread that these embalmers, predominantly men, were able to form a new profession that pushed women out of their

preparatory roles. Moreover, the specialized knowledge that women possessed was devalued as “local knowledge” (Rundblad, 1995, p. 188). As Fletcher (2018) notes, Habenstein and Lamers contribute to this devaluation by misrepresenting the history of shrouding women. Instead, they argue that women possessed a “rough skill” and only provided “assistance” to coffin makers and grave diggers. Fletcher argues that the history of the shrouding women is minimized when they are presented as merely helping figures, as this notion suggests that their “presence was primitive to the more scientific mortuary science that was to come” (2018, para. 8). In contrast to Habenstein and Lamers, Rundblad (1995) provides a very different account of shrouding women. According to Rundblad, they possessed specialized skills acquired over years of tending to the dead. In addition, they altered their care in relation to the effects of decomposition or disease, as well as tended to those who were disfigured or discoloured in death (p. 179). Meaning that shrouding women had to understand the timing of burial and climatic conditions that could impact the presentation of the body, a task Rundblad describes as being a specialized skill (1995, p. 179).

When undertaking became a specialized occupation by the mid-nineteenth century, shrouding women were relegated to a secondary place (Rundblad, 1995, p. 181). Marked by education and scientific prestige, “undertaking began increasingly to reflect the spirit of business enterprise, other categories of tradesmen, craftsmen and functionaries came to dominate the occupation” (Habenstein & Lamers, 1981, p. 238). Despite women’s long-standing role as caretakers of the dead, newly professionalized undertakers looked to sexist notions about women’s “nature” in order to argue that women were not fit to tend to the dead. Embalming, as a scientific means of caring for the dead, was cited as a reason why women should not be allowed to pursue a career in mortuary sciences because women did not have the intellectual or

psychological capabilities to prepare the corpse for burial (Rundblad, 1995, p. 181). Women are still devalued in death care today. Thus, it is important for scholars writing about women's contemporary involvement in mortuary sciences to understand how the discourse of care often reduces women to archetypal motherly stereotypes. In this thesis, I seek to connect the relationship between death doulas and care-work discourse.

While undertaking became popular during the late nineteenth century, many families could not afford undertakers' services. Consequently, many people continued to practice home funerals in some parts of Canada until the mid-twentieth century (Arnup, 2018, p. 8). This period is marked by a substantial increase in population and by incredible achievements in the fields of science and medicine, which greatly decreased mortality rates through technical advancements that improved survival rates during surgery.<sup>4</sup> It was not until this period, the post-World War II era, that death shifted to hospital settings. This is due in equal parts to increased wealth and economic prosperity as well as legislative changes in provincial and federal governments. With Canadians now having access to better quality hospital services and non-emergency procedures covered by physician's care, death care also shifted to a hospitalized setting.<sup>5</sup>

But, rather than focusing attention on managing the physical symptoms of death and dying, medicine focuses on life-saving measures and curative medical practices. Therefore, while modern medicine has increased life expectancy, it has also increased the likelihood of living with complex, chronic illnesses late in life. Nonetheless, despite the high number of older adults dying

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<sup>4</sup> Building on Tommy Douglas' lead in improving access to medical and hospital care in Saskatchewan, the *Hospital and Diagnostic Services Act* of 1957 passed legislation and provided coverage for hospital services. In 1966, the *Medical Care Act* extended coverage to physicians' fees (Arnup, 2018, p. 9).

<sup>5</sup> According to Arnup (2018), whereas only 30% of Canadians died in hospitals in 1930, this number increased to 77% by the 1990s (p. 9). Moreover, the numbers in the 1990s vary significantly by region, with Manitoba having the highest rate of hospitalized deaths at 84% and Nunavut the lowest at 37% (p. 10).

alone in hospitals, Morrison (2018) argues that “[m]ost healthcare professionals lack knowledge and skills in the core palliative care domains—pain and symptom assessment and management, communication, care coordination, and most Canadians are only vaguely aware of the benefits of palliative care and how and when to access it” (p. 63). Due to the lack of access to palliative care in Canada, the majority of those at the end of life die in hospitals, where the training of staff is focused on providing acute care rather making death as painless as possible (Arnup, 2018, p. 26). In many cases, hospital environments are not suited for death nor set up with the comfort of the dying in mind. As Arnup (2018) notes, the “transition from home to hospital often meant the patient dying alone in a foreign environment, away from friends and family” (p. 10). Presently, patients dying in unfamiliar environments separated from their loved ones is currently being exasperated by the COVID-19 crisis.

As Ariès (1981) argues, once a community-oriented event, death “steadily contracted until it was limited to the closest relatives or even to the couple, to the exclusion of children” (p. 558). Death’s disappearing act in contemporary Canada has a variety of impacts. For society at large, the absence of death in daily life has contributed to the perceived increase in fear of death. As a result, Canada, and Western nations as a whole, are death-phobic. Though the fear of death may seem natural, it is important to note that seemingly benign understandings of death inform societal phobias, social institutions, state-sponsored violence, and the death industry. Societal understandings of death and death phobia underpin much of our conscious and unconscious thoughts and actions; these oftentimes concealed phobias pathologize death in a variety of ritualized behaviours such as seeking immortality, the censoring of death-centric conversations, and the medicalization of death and dying. Arnup (2018) cites the fear of death as one of the major reasons dying individuals are admitted or readmitted into hospitals. As such, death itself

has become professionalized. Immediately after death, families are escorted out of the room and the care for the dead moves from the hospital to the funeral home.

### **Contemporary End-Of-Life and Funeral Care in Canada**

On July 1<sup>st</sup>, 2019, there were approximately 6,592,611 recorded Canadians aged sixty-five and over, making baby-boomers the majority of seniors for the first time in Canadian history (Statistics Canada, 2019). By 2068, seniors are predicted to make up about 30% of the population, a 17% increase from 2018 (Statistics Canada, 2019). The numbers show that there is a substantial aging population in Canada, and while modern medicine has effectively lengthened life expectancy, it has also increased the complexity of one's physical and psychological medical life. Additionally, Kahana and Kahana (2014) report that the wants and expectations of care for baby boomers are changing. Not only did they find that baby boomers take more initiative with approaching their doctors about their medical concerns (p. 380), they also report that baby boomers "value and pursue social engagement and healthy lifestyle behaviors and have high expectations for wellness and independence in late life" (p. 381). Kahana and Kahana's findings indicate that baby boomers are outspoken about their health and conventional end-of-life care may not be able to suit their unique needs. However, it should be noted that Kahana and Kahana do not include demographic data about their subjects, in order to speak with greater confidence about their claims further research needs to be conducted to obtain greater nuance into the wants and needs of boomers across socio-economic classes and cultures in Canada.

Increased family mobility, lack of adequate and affordable access to at-home palliative care, and a growing number of individuals living alone are all cited as reasons why a majority of people in Canada, upwards of 70% according to the Canadian Hospice Palliative Care Association (CHPCA) (2014), are dying in hospitals (p. 1). This is despite approximately 87% of

Canadians aged 55 and older indicating that they want to die at home (2014, p. 1). Outside of the home, hospices provide a location for acute palliative care for dying individuals. However, a CHPCA (2014) survey found that only about 25% of dying patients in Canada have access to hospice palliative or end-of-life services, depending on their location in Canada (p. 1). CHPCA also found that an even fewer number of individuals have access to bereavement services (p. 1). Considering the growing number of aging Canadians and the complexity of their needs and desires, palliative care is in need of a paradigm shift. For example, there could be more of an effort to develop structures and approaches that allow patients to die comfortably in their location of choice, such as the home, and not necessarily in a default location such as a hospital or care home.

Constraints on the Canadian health-care system make dying at home impossible for many. For example, some regions (particularly rural locations), either have shortages of physicians, nurse practitioners, nurses and palliative care-workers, or these same workers are reluctant to make home visits (Arnup, 2018, p. 19). However, a study by Tanuseputro et al. (2018) reported that:

Receiving at least one physician home visit from a non-palliative care physician was associated with a 47% decrease in the odds of dying in a hospital. When a palliative care physician specialist was involved, the overall odds declined by 59%. Location of death is strongly associated with end-of-life health care in the home. Less than one-third of the population, however, received end-of-life home care or a physician visit in their last year of life, revealing large room for improvement. (p. 1)

Tanuseputro et al.'s findings indicate that there is great value in community-based, at-home end-of-life care. The inability to implement such evidence-based care models indicates a failure

in Canadian health-care systems; it seems that Canada is not prepared to adequately provide care for its aging population, especially as the number of seniors is predicted to rise. This not only has impacts on dying patients, but on their families too.

According to Arnup's (2018) survey of Canadians aged 55 years and older, aging populations increasingly want to die at home, pain free, and with dignity (p. 30). Unfortunately, for many these desires are not met due to a lack of services and supports, and the significant likelihood that aging individuals will spend their last few weeks of life in hospitalized settings. Many families feel helpless and get lost trying to navigate health care systems with their loved ones. Moreover, increased geographic mobility, decreasing birth rates, and the decline of multi-generational households post-1960 have made at-home palliative care difficult, if not impossible (Arnup, 2018, p. 22). Furthermore, care-work is frequently expected to be done by women-identified (mothers, daughters, sisters, nieces, etc.) family members (Arnup, 2018, p. 22). These women experience the brunt of familial care "burn out" when not able to meet these expectations and the person dying can feel like a "burden" to their family (Arnup, 2018, p. 23).

The general Canadian population's wishes of dying pain free and at home are aspects of what has been termed a "good death." A good death is described as "a death that is free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Institute of Medicine, 1997, p. 27). However, while the "good death" is spoken of in generally positive language by proponents of death positivity, many of my participants took issue with the term. I discuss their varying opinions about the "good death" in Chapter 4.

No system operates in an absence of power and the death-industry is no different: cis-gender, white, heterosexual men are the most likely to obtain a good death. That is, in Canada,

one's race, gender, and socio-economic status greatly affect one's ability to access affirming palliative and funeral care. Racism, sexism, homophobia, and transphobia embed medical institutions such that, according to Romano (2018), "our medical system is structured to individually and systemically favor white physicians and patients in ways that white people are trained to ignore" (p. 262). It is important to understand that these inequalities are structural and systemic, as Romano continues, "most white doctors do not think race affects them or their clinical decisions and are taught to ignore their own racial privilege in favor of a meritocratic social myth" (p. 268). In their study on medical racism in Canada, Lingard, Tallett, and Rosenfield (2002) found that the medical residents believe that medicine is an unbiased, "culture-free" field and that "cross cultural misunderstandings did not affect their encounters and that in Canada people were more progressive and less judgemental" (p. 334). Their research not only confirms the existence of a widely held belief that science and medicine are objective fields free from bias (p. 334), but also suggests that physicians ignore their white privilege and can thus perpetuate systemic inequalities in medical systems.

Fletcher (2019) notes that colonialism has "marginalized, trivialized, and outright negated deathways and death practices, of nations, cultures and persons deemed 'other'" (para. 3). When scholars of death discuss and problematize contemporary death practices, it is integral to address white privilege and call attention to the focus on Eurocentric death practices in North America. Canadian health care and funeral systems are built on Eurocentric ideas about death and mourning. During colonization in the Americas, colonizers used differences in funeral rituals and death care as tools of forced assimilation (Seeman, 2011). An example of this is an amendment to the Indian Act (1876): in 1884 the "Potlatch Law" banned the practice of Indigenous ceremonies. This law impacted Indigenous communities in Western Canada in particular.



Depending on the nation, potlach ceremonies were commonly held to mark birth, deaths, weddings, and coming-of-age ceremonies (Cole & Chaikin 1990, p. 5). Not repealed until 1954, the Potlach Law was one of the many violent acts of assimilation that left Indigenous nations unable to practice mourning traditions and funerals safely. Before, during, and after the repeal of the Potlach Law, “Indigenous people remained under mental siege from colonial governments, assimilationist tactics, church and government residential schools and Christian missionaries” (Wesley-Esquimaux & Smolewski, 2004, p. 25) who sought to use Christian faith and ritual as a tool of forced assimilation.

It is difficult to provide an overview about Indigenous perspectives on death and end-of-life due to the lack of writing on the topic. As Anderson and Woticky (2018) explain, “government policies aimed at cultural extermination and assimilation resulted in a tremendous loss of Indigenous knowledge, including end-of-life practices and ceremonies” (p. 51). To this point, Anderson and Woticky argue that the negation of Indigenous deathways has left Indigenous communities without access to hospital or hospice care that would enable them to practice their deathways without their trivialization. As they explain, “The absence of a word for death in most Indigenous languages underscores how differently the end-of-life experience is constructed by Indigenous people. The colonial worldview frames death through a linear, biomedical, and physical lens [whereas] Indigenous people view themselves as a spirit having a human experience” (Anderson & Woticky, 2018, p. 51). A medicalized death, as argued by Anderson and Woticky, is another avenue by which colonial societies forcibly assimilate Indigenous communities and nations. In short, it is important to understand that white North American death practices alienate many communities. Considering the oral nature of Indigenous knowledge, Anderson and Woticky stress that “rediscovering traditional death ceremonies,

increasing access to cultural supports, enhancing death education, and improving relationships with health service providers are of great importance” (p. 51).

Centuries of colonial violence and genocide have had a deleterious impact on Indigenous health, making Indigenous individuals “experience much higher rates of morbidity and mortality and a much lower life expectancy than any other group in Canada” (Arnup, 2018, p. 15). In addition to having complex health concerns, Indigenous women are disproportionately the victims of violence and murder, and many Indigenous youth (Inuit youth in particular) experience among the highest suicide rates in the world—approximately eleven times the national average (Arnup, 2018, p. 16). There are also a distinct lack of health resources for many Indigenous communities, especially those in rural locations, who reportedly have to drive hours just to receive hospital treatment (Arnup, 2018, p. 15).

Moreover, Bourassa (2012) argues that the geography of funeral homes and hospitals suits the predicted needs and rituals of the dominant white Christian population, which alienates those who deviate from those practices, including many Indigenous communities. As Bourassa observes, hospital settings are ill-equipped for Indigenous deaths due to the lack of physical space; since hospital rooms are designed with the nuclear family in mind, extended family are excluded from the process, leaving “thirty to fifty people in the waiting room” (para. 8). The lack of support for Indigenous communities indicates not only a failing in health care systems, but also the perpetuation of colonial violence and genocidal practices.

Many critiques of North American deathways, a majority of which have been authored by white scholars, are exclusionary, as they often suggest alternative funeral care approaches that are not attentive to marginalized histories, racial or ethnic, or religious differences. Anderson and Woticky (2018), Bourassa (2012), Arnup (2018), and Fletcher (2019) are among those scholars

who have provided critiques of Eurocentric health care practices, but within a hyper focus on Eurocentric death studies. Green burial and wildlife protection advocates are a case in point, illustrating the uneven respect for burial sites. Green burial sites or ‘conservation burials’ are touted as an avenue for wildlife and ecological conservation, the assumption being that if a body or bodies are buried on a site then they are unlikely to be removed for developments or construction projects. To qualify for a conservation burial site, which is described as “chaining yourself to a tree post mortem” (Order of the Good Death, n.d., para. 9), individuals must be buried without embalming fluids or vaults and in a biodegradable casket and one not made of endangered wood or burial shroud (Prairie Creek Conservation Cemetery, n.d., para. 1). Additionally, conservation burial sites must “commit burial fees to pay for land acquisition, protection, restoration, and management” (Prairie Creek Conservation Cemetery, n.d., para. 2), meaning that the costs of a conservation burial should be put towards further conservation efforts in the cemetery. Though there may be nothing inherently wrong with committing to sustainable burial practices that do not pollute the natural environment, not all bodies and burial site practices are equally respected. The desecration of Indigenous burial sites by colonisers for museums and universities was a common practice up until the 2000s. Even today, projects such as the Dakota Access Pipeline and the ongoing situation in Oka, Quebec have shown that there is no universal respect for burial sites. Infringement on burial sites by the state has much to do with who is buried there. As such, natural burial from the angle of conservation must be contextualized within an understanding of the ways whiteness and colonial histories greatly influence how burial sites are perceived, preserved and interacted with.

It is also important to consider how mainstream end-of-life practices can harm other marginalized groups. For example, Colby (2017) and Weaver (2018) found that injustices are

committed against trans individuals after death as they may not have had the resources or knowledge to pre-plan their affairs before death. Jennifer Gable and Christopher Lee are two examples of trans individuals who were buried and given obituaries under their dead names<sup>6</sup> (despite having legal name changes); and, in Gable's case, she was presented as her assigned-gender-at-birth in the casket (Colby, 2017). This is what Weaver (2018) has termed the "detransitioning" of trans individuals after death (p. 2). Colby notes that funeral directors found that unless the deceased had any plans formally set in place, the next of kin are able to do whatever they choose with the disposition of the body, which may not be supportive of one's sexual or gender identity. Death positive and trans activism intersect with campaigns for education and cultural competency in end-of-life care. As Weaver notes, this is done by

recognizing, publicizing, and working to prevent the mortal dangers that transgender women [and men] face due to transphobic violence and suicide, advocating on the behalf of trans elders, educating about end-of-life issues, and acting to make changes in federal and state law that stop the lives and histories of transgender women from being altered, silenced, and erased. (p. 8)

Greater access to knowledge about one's end-of-life options and advance care planning (the act of planning for death and dying) can be key measures for maintaining one's autonomy in death and dying (Speak Up Ontario, 2019).

Advocating for cultural competency and anti-oppression training in end-of-life care extends beyond hospital care. Activists are raising awareness about the injustices that can occur in the funeral parlour. While death doulas are neither medical nor funeral professionals, their

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<sup>6</sup> A "dead name" is "the birth name of someone who has changed it. The term is especially used in the LGBTQ community by people who are transgender and elect to go by their chosen name instead of their given name" (Dictionary.com, n..d)

emerging role in end-of-life planning and care means they will be working with vulnerable groups who may be not only grieving, but also fearful. As one of my participants noted, marginalized individuals and groups may hire death doulas to assist in planning their end-of-life and funeral arrangements after having experienced medical racism and/or transphobia when trying to obtain healthcare services. For all of these reasons, studying death doulas (whose main role is in assisting with advance care planning) is crucial to determining whether or not they can provide tailored information to help individuals (especially marginalized individuals) make informed choices about their funerary and end-of-life-care options, potentially as an intervention against hegemonic systems that actively cause harm. However, as previously noted, death doula work may have an uncomfortable connection to cultural appropriation. The question then arises: To what extent are death doulas able to provide their clients with culturally safe care? As I discuss in Chapter 4, the level of core competencies and consistent training that death doulas receive emerges as one influential factor in determining this outcome.

A description of the contemporary landscape of death and dying in Canada is incomplete without a brief snapshot of the funeral industry, especially the policies and practices of major funeral conglomerates. In Canada, Arbor Memorial Inc. operates over 92 funeral homes, 41 cemeteries, and 28 crematoriums in every province across Canada, with the exception of Prince Edward Island and Newfoundland and Labrador (Arbor Memorial Inc.). Arbor Memorial Inc. brings in over 140\$ million in revenue annually and serves approximately 18 000 Canadians every year (Death Inc, 2017). Arbor Memorial Inc. has a monopoly in Canada on funeral homes, streamlining services and interment across provincial borders. As a result, there are few options for consumers who are interested in a more hands-on or eco-conscious approach to a funeral. A CBC Marketplace Investigation into Arbor Memorial funeral homes in Ontario found workers

(who make a baseline salary plus commission) upselling customers and “preying on grief and guilt” (Death Inc, 2017). CBC investigators also noted a push for embalming for “body identification” purposes and for families wishing to see the body before cremation, despite there being no need nor any law making embalming mandatory (Death Inc, 2017). In short, the current death landscape includes a population largely unaware of its rights and funeral workers who often pressure families to maintain “sanitary” conditions under what they falsely suggest are mandatory legal obligations. Writing within and in response to this context, I examine how death doulas negotiate the hegemonic beliefs about death and dying described above and what alternatives they might provide for end-of-life and funerary care.

### **The Death Positive Movement**

As the largest component of the death reform movements, the death positive movement seeks to challenge the fear of death by advocating for an open stream of knowledge about the systems and processes of death. The death positive movement was founded by Caitlin Doughty in 2011 and became the central philosophy of “The Order of the Good Death,” an academic, artistic and activist movement comprised of “funeral industry professionals, academics, and artists who [are] exploring ways to prepare a death phobic culture for their inevitable mortality” (Order of the Good Death, n.d.). Comprised of an eclectic community of “death professionals,” mortician Sarah Chavez states that the overarching goal of the death positive movement is to “portray death in its entirety” (Chavez, 2016 ) so that societal attitudes about death shift away from cultural denial to an acceptance of one’s mortality. Overall, the goal of the death positive movement is to eliminate death phobia from Western society in order to better engage with death in sustainable, ethical, and emotionally fulfilling ways.

Current literature suggests that death doulas are often pooled into the death positive category. Thus, a central aim of my thesis is to chart more fully this reported connection between the death positive movement, death doulas and death positivity. As I consider in Chapter 4, death doulas, including many of my participants, and death positive activists use similar language such as “reclaiming death,” “good death,” and “death literacy.” Further, many death doulas are involved with death-positive associated events like death cafés. The Death Café is a multi-national “grassroots organization driven by volunteers who feel strongly about creating a safe space for people to meet, eat cake, drink tea or coffee, and discuss death with no agenda, objectives or themes” (Baldwin, 2017, p. 26). On the surface, there appears to be much in common between the motivations of the death positive movement and the aims of death doulas; however as I discovered in my interviews, not everyone wants to be associated with death positivity. As noted, the findings from the interviews suggest the existence of multiple death reform movements that overlap. While the death doula movement, the community death care movement, and the alternative death movement can be seen as falling under the umbrella of death positivity (as it is the largest, most well-known movement associated with death reform), it can also be argued that the aforementioned movements are somewhat separate from death positivity.

The death positive movement is in fact a relatively small academic field with most writers taking to online platforms such as blogs to discuss death in all of its manifestations. It is specifically worth noting the medium of much death scholarship. With the exception of death salons, which are academic conferences that “bring together intellectuals and independent thinkers engaged in the exploration of our shared mortality by sharing knowledge and art” (Death Salon, n.d.), the vast majority of scholarship is found on online blogs and art collectives.

With multiple platforms sharing the similar goal of challenging “a death denying culture” by “opening up conversations with the public about death” (Death Salon, n.d.), this scholarship aims to make readers question death phobia in our culture and provide them with knowledge so that they can make informed choices about their end-of-life and funerary arrangements. In this sense, aspects of the death positive movement can be seen as following the tradition of activist scholarship (Sudbury & Okazawa-Rey, 2009), such as antiracism, feminism, social change, and disability studies, among others.

The open knowledge about the workings of the death industry that is appearing on online platforms appears to be resonating with readers. Tim Hewson, co-founder of Legal Wills, a website that allows users to plan their death arrangements online, found that in 2009 only 0.5% of users were under thirty years old. In 2019, that number has jumped to 12% (cited in Juric, 2019). This is a substantial increase, indicating that young people are perhaps confronting death in ways previous generations have not (Juric, 2019). As the landscape of death and dying shifts in North America, especially among young people, more and more individuals are interested in hands-on, community-oriented approaches to death and dying. This means there likely will be a greater demand for at-home palliative care options and funerary services beyond traditional burial and cremation in the near future. For consumers who want access to a green funeral or to a death doula who can help prepare a loved one for a death at home, these options are often not available to them due to the lack of choice in home care and funeral services. While those in highly populated areas of Canada, such as Vancouver or Toronto, have access to death doulas



and green burial options (even then, the options are still limited<sup>7</sup>), those in rural locations have fewer options (and in most cases, no options) for access to palliative and funeral care centred on reconnecting with death in community-oriented approaches. The lack of options in the funeral industry speaks to our current neoliberal moment, as corporations such as Arbor Memorial Inc. are able to create a monopoly and accumulate huge profits with little regulation. This lack of options has widespread implications; beyond alienating individuals from their own personal, autonomous relationship with death and mourning, it also enables our current funerary systems to continue potentially unethical business practices and further cement unsustainable bodily disposal methods that harm the environment.

The death positive movement strives to reframe societal relationships with death and approach the subject of death tactfully, as a peaceful death by aging is not a reality for everyone. Fletcher created the blog *Radical Death Studies* to address whiteness in the field of death studies. In it, she reminds readers that systemic oppression, for people of colour specifically, is a factor in one's likelihood of experiencing violence or death at the hands of state authority.<sup>8</sup> For these reasons, it is integral that death scholars utilize an anti-oppression framework in their analysis of the systems that manage end-of-life care and death, in order to outline how obtaining a good death is in itself a privilege. This privilege depends on many factors, including wealth, disability, gender identity, and race. In sum, systemic oppression correlates with negative social

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<sup>7</sup> In Canada, only British Columbia and Ontario have green funeral options. However, there are only three providers in Southern Ontario (in Picton, Coburg, and Niagara) and three in British Columbia, all on Vancouver Island (Green Burial Society, n.d.).

<sup>8</sup> It was only very recently, in June 2020 that the Ontario Health Coalition published a formal statement naming anti-Black racism as a “public health crisis” in direct response to the protests in the wake of George Floyd’s murder at the hands of Minneapolis Police (Ontario Health Coalition, 2020).

determinants of health, i.e., making certain populations disproportionately vulnerable to heightened rates of disease and violence *and* less access to services that can provide relief.

As Fletcher (2018) points out, death scholars often critique hegemonic systems that manage death and funeral care from a white, Eurocentric perspective. For example, in her popular book *The American Way of Death* (1963), Jessica Mitford critiques the *white* American way of death, which is hardly universal. Fletcher states that Mitford's argument lacks a critical engagement with race, gender, and immigration status (Fletcher, 2018, para. 5). Echoing Fletcher's claims, in her investigation into the history of Black funeral directing in America, Smith (2010) found that, because they were not included in Mitford's study, Black funeral directors were not concerned with Mitford's findings of corruption and overselling by white funeral directors. Moreover, they felt that the allegation of corruption did not apply to them (p. 156). Mitford published her book during the middle of the Civil Rights Movement at the time when many Black funeral directors were involved with activism and had more pressing concerns than Mitford's allegations against white funeral directors (Smith, 2010, p. 153). With this in mind, Fletcher (2018) argues that over-selling customers on funeral costs would have been "counter intuitive" since "African American funeral directors fought for justice; they did not have time to collectively concoct schemes to exploit the bereaved" (para. 10). As such, the stereotypical image of the exploitative funeral director is not a universal experience.

A substantive branch of the death positive movement is concerned with the impact of the death industry on the environment. Writers such as Harris (2007) and Martyn-Hemphill (2013) illuminate the consequences of the commonplace practices of the funeral industry. Outside of the financial and psychological harms in upselling clients into services they do not need, there are lived environmental harms in embalming, burial, and crematory practices that are crucial to

mention given our current climate crisis. Formaldehyde, a major ingredient in embalming, has been linked to heightened cancer rates and upper respiratory problems in mortuary workers (Costa et al., 2008, p. 40). While embalming seeks to preserve a corpse, it does not fend off decomposition forever; as corpses break down, environmentalists worry about toxic leakage from “deteriorating plastics from insulation and lining, formaldehyde and metals from the body” (Huffman, 2010). As Canada experiences the effects of climate change, it is becoming crucial that our societies rearrange themselves in sustainable ways; and the funeral industry is no exception. Death doulas can provide information that allows clients to make informed choices about their funerary options, which perhaps explains why two death doulas (Alua Arthur and Angela Hennessy) are part of the team of consultants for Recompose<sup>9</sup> (n.d.). The success of Recompose and the legalization of human composting in Washington State illustrates that change is occurring in the funeral industry and death doulas (at least in Washington State) are involved in decision making for alternative forms of death care.

Having provided an overview of the death positive movement, their scholarship and activism, I want to note that while the death positive movement is one of the most popular death reform movements, it was not very popular amongst my participants. In particular, many of the participants found the language of “death positivity” and “good death” to be alienating and potentially upsetting to their clients. While the opinions of these participants should not be applied to the broader death doula community, their discomfort with death positivity indicates a need to add nuance to the discussion of death reform movements that exist outside of the death

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<sup>9</sup> Recompose is a company founded by Katrina Spade that offers “natural organic reduction” (the process of converting human remains to soil). The team at Recompose states that, “In addition to creating a system that will gently return us to the earth, we encourage participation and strive to make the experience transparent and meaningful for everyone” (n.d.).

positive movement. For more information on the participants and their relationship to death positivity, please refer to Chapter 4.

### **Conclusion**

It is important to understand both the historical and contemporary landscapes of end-of-life care in North America to contextualize the participant perspectives and findings of this study. Therefore, in this chapter, I explore the concept of a death doula, including what we know so far about their role and place in end-of-life care and funerary movements. I also review historical understandings of death traditions and the ways scholars conceptualize care-work in highly gendered and Eurocentric ways. The existing literature about death doulas is limited and does not provide a cohesive view of the profession. Moreover, there does not appear to be a standard practice to which death doulas adhere. That said, the literature does suggest an alignment between death doulas and the death positive movement -- a suggestion that is partially contradicted by the information I collected in this project, as we shall see.

## **CHAPTER 2: THEORETICAL APPROACH, PHENOMENOLOGY, AND RESEARCH DESIGN**

In this chapter, I provide a detailed analysis of the methodology, epistemological perspectives, research design and implementation used in this thesis. I build this thesis around the thoughts, perspectives, and experiences of six interview participants using feminist phenomenology and interpretative phenomenological analysis. As a mode of study that examines the lived experiences of its subjects, phenomenology is crucial in gathering first person insights into the phenomena being studied. In this chapter, I clarify how feminist phenomenology distinguishes itself from other branches of phenomenology and discuss how it informs my approach to interviewing and data analysis. Lastly, I provide a reflective account of feminist phenomenology.

### **Methodologies and Theoretical Approach**

#### ***Phenomenology***

Phenomenology was popularized by Edmund Husserl, Martin Heidegger, Jean-Paul Sartre and Maurice Merleau-Ponty among others. Recent definitions describe phenomenology as “the study of human experience and of the ways things present themselves to us in and through such experience” (Sokolowski 2000, p. 2). Phenomenology has also been defined as “the study of structures of consciousness as experienced from the first-person point of view” (Smith, 2008). These two definitions build on classic interpretations of phenomenology as popularized by Edmund Husserl (1859 – 1938) during the early part of the twentieth century. Husserl was concerned with the concept of objectivity and how one obtains objective knowledge. The very idea of objectivity poses an epistemological conundrum: how can knowledge be grounded in truth and logic when it is up to humans (who can arrive at a variety of conclusions) to interpret?

### ***Feminist Phenomenology***

If phenomenology, in its most basic form, contextualizes knowledge from lived experiences, feminist phenomenology builds on the foundations of traditional phenomenology by asking how experiences of gender, race, sexuality, class, and dis/ability “inform phenomenology as a philosophical project” (Káll & Zeiler, 2014, p. 2). In particular, feminist phenomenology asks participants to reflect on their embodied experiences, constructions of identity, and the relationship between embodiment and broader phenomena. Phenomenology is important to feminist scholarship as it allows the researcher to obtain a first-hand account of how social categories such as gender, sex, and class influence the experiences of participants—in this research, death doulas (Simms & Stawarska, 2014, p. 2). Fisher and Embree (2000) argue that, despite not including critical feminist analyses traditionally, phenomenology shares with feminism “a commitment to descriptive and experiential analysis” (p. 33). In the case of feminist phenomenology, participant reflexivity enables the researcher to interpret participant experiences in relation to larger phenomena. Such research could involve narratives of domestic abuse for a qualitative study on domestic abuse; the experience of growing up with generational trauma to discuss settler colonial violence in Canada; and the experience of being disabled in an able-bodied world as evidence for a study assessing discrimination and accessibility, among others. In my particular case, feminist phenomenology allows me to record participants’ first hand experiences and relate the phenomena to broader social concerns.

### ***Intersectionality***

Intersectionality is a theory developed by Crenshaw (1989) and outlined in her article “Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Colour.” Intersectionality describes the ways oppressions are interconnected and cannot be separated from another when discussing personal or collective experiences navigating life.

Central to the theory of intersectionality is the understanding that individuals can occupy multiple identities; these interlocking identities can combine to create unique experiences of discrimination. As this research concerns themes of monetization, professionalization and care-work, feminist phenomenology and intersectionality together provide a way to analyse the experiences of participants in relation to broader social contexts.

A common thread in feminist research more broadly, is the question of power as it moves in the spaces between the participant and the researcher. Rather than asserting that the researcher is objective and not involved in knowledge production, many feminist phenomenologists try to account for their positioning during the analysis. One of the best examples of this can be read in Presser's article "Negotiating Power and Narrative in Research: Implications for Feminist Methodology" (2005), in which Presser recounts her experience interviewing incarcerated men convicted of violent crimes. There are a number of factors at work in this study that complicate the relationship between Presser and her participants, and Presser's account of her experience illustrates how power relations during the interview process can alter the findings of the research. Presser attends to incarcerated men's lack of autonomy, and acknowledges that as a researcher she wields power over the conversation and over how readers will perceive these men. In this example, Presser (2005) elicits comments, including a stalking threat, which are directly related to her identity as a cisgender woman (p. 2085). If a man had interviewed the same men for the same project, it is unlikely that he would have received threatening comments of that manner or been given nicknames like "baby-girl." Other methodological approaches do not typically consider the feelings and experiences of the researcher as evidence. However, Presser can use feminist phenomenology to interpret the nuances in this complicated web of power, and by using this approach, account for participant and researcher experiences as part of the analysis.

I entered my research with the awareness that as a white, gender non-binary researcher I am in a position of power in relation to my participants, as I am responsible for analysing and presenting their interviews in addition to holding a privileged position in society more generally due to my race. Similarly, I also entered this research mindful of the ways the participants are in a position of power over their clients. As a group of mostly cisgender, heterosexual, middle-aged white women, they occupy privileged social positions and this privilege often comes with certain worldviews that disregard and/or actively support systemic discriminations. Further, their job as death doula requires them to be involved with vulnerable individuals who may be dying themselves, or who is related to or a friend of someone who is dying.

In my own work, as mentioned above, I recognize the power disparity between the participants and myself as the researcher. In order to mitigate these power disparities, I made myself available to my participants before, during and after the interviews in order to answer their questions and address their concerns. During the interview, I made an effort to have the participants guide the conversation to where they felt most comfortable. In order to make sure the participants were comfortable with the results of the interviews, I sent them transcripts of the interviews to edit as they pleased so they could have ownership of their words and the ability to alter them before I began analysing the data. By allowing the participants to view and edit the transcripts, I practiced Lawless' (1993) concept of "reciprocal ethnography," which is described as the act of seeking feedback from participants in order facilitate a democratic process during data collection.

Though death doula are considered non-medical support, their involvement with clients who are dying means that their experiences could be comparable to those who work in medicine. Researchers in the field of medical phenomenology have integrated feminist phenomenology to



discuss experiences of illness (Carel 2016; Svenaeus 2000; Benner 1994), death (Haddow 2005), pain (Leder 1984; Morrissey 2011), and birth (Oksala 2004). Käll and Zeiler (2014) claim that medical phenomenology often “focuses on first-person experience” (p. 4), but also relies on empirical or clinical evidence to integrate experiences of death, illness, or alienation “with the aim of theoretical elaboration and conceptual development” (p. 4). The goal of studying the first-person accounts of those experiencing illness or of frontline medical workers is to decipher patterns and potentially build better supports to address their needs or potentially identify dangers or shortcomings. Feminist phenomenology adds an analysis of systemic oppressions that traditional phenomenology with its white, male biases has neglected.

### ***Interpretive Phenomenological Analysis***

Since the focus of this research is care-work, interviewing individuals working in this field is crucial for obtaining insights into the lived reality of death doulas. With this in mind, I chose to use interpretative phenomenological analysis (IPA) as my principal approach to data analysis. IPA is a qualitative approach to data analysis that aims to “provide detailed examinations of personal lived experience” (Smith & Osborn, 2015, p. 1). IPA was first popularised by Jonathan Smith during the 1990s, and expanded upon by Smith, Flowers, and Larkin in their book *Interpretive Phenomenological Analysis: Theory, Method, and Research* (2009). While there have been many articles written about IPA, Smith, Flowers, and Larkin’s text is one of the few book-length studies devoted to the approach. Moreover, IPA is appropriate for my research project due to its prominence within health and counselling research (Parker 2004). While IPA is certainly not the only method used within health and counselling research, it is particularly well suited for this focus on care-work and for analysing the findings in relation to larger social contexts such as the gendered politics of care-work, medical racism, and cultural appropriation. In addition to this thematic fit, IPA provides a practical set of guidelines,

including recommended sample size, suggestions for interview style, and advice for interview analysis.

### ***Phenomenological Reduction***

A key step in my process was phenomenological reduction. Phenomenological reduction is a process of unpacking a particular phenomenon by analysing the layers of meaning embedded in participant statements about that phenomenon (Gilstrap, 2007). I used Smith, Larkin, and Flower's approach to data analysis, as they suggested making descriptive comments about language usage (what was said and how it was said), as well as comments about broader concepts alluded to by the participants. I was able to account for tone as well as content. Thus, I transcribed the interviews by listening to the recording, and typing the conversation manually. Transcribing the interviews was an integral step to my data analysis; in transcribing each word, I was able to revisit the interviews and gain insights that had not occurred to me during the initial interview.

The second step was reading each transcript and making detailed notes about emerging themes. To pinpoint emerging themes and better understand which ones were most important to the participants, I read each transcript several times. Furthermore, I read the transcript while listening to the recording again, which further cemented participants' tones within my mind. I did this by recording non-verbal cues such as pauses and hand gestures within square brackets during the interview process. While time consuming, these steps were invaluable. They allowed me to think further about emerging themes that stood out during the first read through of the interview. I was then able to move to the next step, called horizontalization where one composes a list of themes by making a list of non-repetitive statements that speak to larger themes in the project (Moustakas, 1994).

Following the interviews, I reflected on what we spoke about and took detailed notes, and began transcribing the interviews the next day. I conducted no more than one interview a day, which allowed me both ample time to transcribe and make reflective notes about each interview. Once the transcription process was complete, I provided participants with the opportunity to review their transcripts and to add, change, or delete information as they saw fit. I then used these participant-approved copies as the basis for my analysis.

Moustakas recommends asking the following two questions to determine whether a statement holds weight and provides critical insight into a given theme: 1) “Does it contain a moment of the experience that is a necessary and sufficient constituent for understanding it?” and 2) “Is it possible to abstract and label it?” (Moustakas, 1994, p. 121). With these questions in mind, I examined select statements from the transcripts and clustered them into categories. As a result, two major themes emerged that would become the focus of my analysis: the role of the death doula in care-work and the monetization of death work. I also identified the sub-theme of death doula education and training. With these questions in mind, I began outlining and writing up my research.

### **Research Design**

When designing this project, I leaned heavily on Smith, Flowers, and Larkin’s (2009) guidelines for using IPA. Those guidelines include drawing from a fairly small sample size (i.e., interviewing between three to six participants); choosing participants from a relatively homogeneous group; conducting semi-structured interviews; and presenting findings from the interviews through “a narrative account where the researcher’s analytic interpretation is presented in detail and is supported with verbatim extracts from participants” (Smith, Flowers, & Larkin, 2009, p. 4). By staying within these guidelines, I was able to gather an amount of data

suitable for a Master's thesis project. I state this explicitly because I find that IPA is quite applicable for smaller research projects and is helpful for novice researchers, such as myself, to gain a footing in the field of gathering data from primary sources.

I recruited participants using a two-pronged approach. First, I approached the Home Hospice Association, an association in Toronto, Ontario that provides a death doula training program, to gauge their interest and ability to provide support for my project. They agreed to advertise my research on their Facebook page and affiliated death doula Facebook groups in December 2019 (Appendix A). To clarify, the Home Hospice Association is not a partner in my research; they were only involved with disseminating my research to a larger audience, and did not know who responded to the advertisement. Unfortunately, because only one individual responded to the advertisement and did not follow up after I responded to them, I concluded that this was not an effective method to recruit death doulas for the study. Second, I emailed information about the study to death doulas who had contact information on their websites. This was more successful in yielding responses from interested parties. In the future, if I were to conduct a larger qualitative study, I would use a snowball approach for participant recruitment.

To be eligible to participate in this study, participants had to 1) be over eighteen years of age, 2) speak English, 3) reside in Canada, and 4) either currently self identify as a death doula or have previously identified as a death doula. The interviews were semi-structured, which permitted participants to guide the discussion, and permitted me to gather richer answers that in turn guided the direction of the research. I wanted to provide the participants with an opportunity to explore what was important to them, so that I could understand their place in, perceptions of, and worries about the landscape of death and dying in Canada, including the scope of death doula work and the death positive movement. The interviews were typically thirty minutes to an

hour in length; however, two interviews stretched slightly longer, with the longest being approximately two hours in length. I recorded each interview on a MacBook Air software application called Audacity. I will keep these interviews and their transcripts in a locked folder on my personal computer for five years as per Memorial University's policy on Integrity in Scholarly Research. In 2025, I will destroy both the interviews and the transcripts.

### **Ethical Considerations**

This research project received approval from Memorial University's Interdisciplinary Committee on Ethics in Human Research (ICEHR) based on the guidelines of the Tri-Council Policy Statement 2 (TCPS 2) in December 2019 (see Appendix B). Prior to conducting each interview, I provided the participant with a consent form outlining their role in the study to obtain consent (see Appendix C). As part of this process of ensuring free and informed consent, I informed participants during recruitment in writing that for this study I would interview them about their role as a death doula, what they perceive as challenges in their line of work, and where they see themselves fitting into end-of-life care in Canada. Before each interview began, I verbally reminded the participants about the goals of the study and the sort of questions I would ask.

In terms of confidentiality, I assured the participants that I would exclude all identifying characteristics from data collection and assign pseudonyms for inclusion in the thesis. I clarified that, as the principal researcher, I alone would have access to the audio-recordings, transcribe the interviews and redact all identifying characteristics from the transcriptions. Confidentiality and anonymity are differing, but related terms, with the former meaning to safeguard information from unauthorized use and the latter meaning to keep the identities of the participants secret (Saunders, Kitzinger & Kitzinger, 2015). Both confidentiality and anonymity are pillars of

ethical research, as individuals have a fundamental right to privacy of information. With regard to anonymity, however, Ryen (2004) states that researchers often are unaware of whether their participants wish to be anonymous. Further to this, Giordano et al. (2007) argue that when researchers act under the assumption that all participants wish to be anonymous, they are acting “paternalistically” and may be denying the participants a “voice that confers personal meaning to their enjoyment to the research and its effects(s), outcomes and goals” (p. 265). In addition, Grinyer (2002) argues that while “mechanisms to protect the identity of research respondents appear to have become central to the design and practice of ethical research” (p. 1), when setting “anonymous” as the default position we may be depriving participants from the ownership of their stories.

To address such concerns, I gave participants the option to be identified by a pseudonym or the option to waive their right to anonymity. Initially, five out of the six participants elected the latter. However, late in the study one participant contacted me to ask to be anonymous, bringing the total of anonymous participants to two and those who waived their anonymity to four. Why did the majority of participants choose to be identified by their name? One interpretation is that they are comfortable with exposure in their role as a death doula and therefore see their inclusion in this study as an opportunity to reach a broader audience, and perhaps even to attract more business. If this were the case, it might be fitting to consider death doulas as freelancers within the ‘hustle economy.’ Another interpretation is that they, like Grinyer (2002) suggests, seek credit for their statements and do not want to lose ownership of their experiences (p. 4). However, in offering an explanation as to why she wished to use her name, one of my participants, Pashta MaryMoon, cited a somewhat different reason: “It is not really possible for me to use a pseudonym... I am fine with my own name.” Here, MaryMoon

references that fact that she is widely known in death doula, or as she puts it, death midwife circles, likely due to her role at the centre of a court case with the College of Midwives of British Columbia for using the term “midwife” in her occupation title. MaryMoon’s circumstances speak to the fact that the death doula community in Canada is rather small, and maintaining anonymity in this community can be difficult. However, despite the majority of participants electing to waive their anonymity, at many points during the interviews they made statements that they wished to keep anonymous or exclude from the study. Overall, these were personal comments or statements that they felt could either harm their career, offend those working in end-of-life care or death doula training courses, or cause general conflict with medical, funeral, or theological professionals in their local region. I cannot speculate on whether default anonymity would have made the participants comfortable enough to allow those comments to be published.

### **Introducing the Participants**

As noted previously, I interviewed a total of six death doulas: Olga Nikolajev, Tamara MacDonald, Julie Keon, “Lucy,” “Jane,” and Pashta MaryMoon. Of the six participants, four resided in Ontario, one resided in Saskatchewan, and one resided in British Columbia. All identified as women and were of a similar age range, with the eldest being sixty seven and the youngest being forty eight. Three participants identified as heterosexual and one identified as bi-lesbian asexual; two elected not to share their sexual identity. As for race, three participants identified as Caucasian, one as Italian-Canadian, one as Canadian, and one elected not to provide an answer to this segment. One, who chose to leave both of the answers blank, described herself as white during the interview. While many of the participants self-identified as Caucasian, I

believe it is pertinent to note that in general, the public at large in Canada today use the term white as opposed to Caucasian.

I can only speculate as to why the questions about sexuality and race, out of all the questions I asked, received a unique set of responses. There are several possible explanations. Firstly, participants might not have understood the relevance of sexuality or race to the study and thus provided no answer or ones that skirted the question altogether. Secondly, participants might have interpreted the question about race and ethnicity as one about nationality; however, there was no indication of this misunderstanding during the interviews. Thirdly, and perhaps most likely, cis-gender, white, heterosexual individuals rarely have to take into account their own identity. As Frankenberg (1993) found in her examination of “white culture,” white women see themselves as members of “no culture” or the “normal culture” (p. 203). This positioning indicates that whiteness is often a “default” setting. In other words, white women can employ acts of “power evasion” wherein the structuring of language erases racial difference in an attempt to avoid “acknowledgment of individual complicity with those very same differences of power or privilege” (Frankenberg, 1993, p. 190). While my participants’ responses seem to be consistent with Frankenberg’s findings, I cannot draw any conclusions without placing the interview portion of the study in conversation with the demographic information. Further, there is also the possibility that those who belong to marginalized groups actively choose not to identify themselves in professional situations.

With the exception of MaryMoon and Keon, who have worked as death doulas for the past four decades and ten years respectively, the other four participants have become “certified” death doulas within the past five years. As such, the relative “newness” of the death doula



profession in Canada would go a long way in explaining the conflicting accounts regarding the death doula's scope of practice and general impact on Canadian healthcare systems.

As reported by the participants, the typical hourly wage for a death doula is under \$100 and is offered on a sliding scale, with the greatest range reported by Nikolajev, whose hourly fee can be anywhere between fifty and two hundred dollars. In terms of advertising the cost of their services, half of the participants post their fees online. For example, on her website *Dying Matters*, Nikolajev notes that she charges \$50 for an initial discussion about death doula services and one hundred dollars for a Planning and Preparing Session. On her website *Guiding Hand*, MacDonald lists the cost of a Base Package at \$2500. A review of Jane's website notes that she charges \$75 per hour for "Private Sessions." Jane also advertises vigiling services at the hospital or home, which she defines as "support and companionship for those at end of life and their families". Notably, Jane is the only participant who explicitly states that there are sliding scale options available on her website. MaryMoon directs her potential clients to contact her directly for fees and services.

### **Conclusion**

To conclude, I used feminist phenomenology and interpretive phenomenological analysis as methodological approaches for this study. To balance concerns regarding privacy while addressing that not every participant necessarily wants to be anonymous, I allowed the option for the participants to waive their right to anonymity if they so desired. Following each interview, I began phenomenological reduction. I transcribed each interview, re-read their contents and made detailed notes about emerging themes. From there, I selected statements and clustered them into categories for analysis.

Overall, the demographic information indicates that the participants are all of a similar demographic background and that the majority of the participants had become “certified” within the last five years. The participants advertise their services primarily online and all offer services on a sliding scale, though that information is not always explicitly stated on their websites. Lastly, the price for sessions with the participants ranges depending on whether or not you are booking a consultation or if you are receiving death doula services. Generally, their fees are under \$100 per hour, although this number can fluctuate. In the case of MacDonald, rather than charging hourly, she charges for an overall package of services.

## **CHAPTER 3: THE ROLES AND RESPONSIBILITIES OF THE DEATH DOULA: CARE-WORK, GENDER AND MISUNDERSTANDINGS**

In this chapter, I begin to explore the findings from the interviews I conducted with six death doulas from across Canada. More specifically, I focus on the roles and responsibilities of the death doula, paying special attention to the ways the participants frame their roles in relation to discourses of care-work and gender. In the process, I begin to address one of my key research questions about if and how hegemonic beliefs about death, gender, and social privilege figure into death doulas' roles in death work and death reform. Key sub-themes that emerged in relation to this topic are the language around the notion of "innate" knowledge and skill, the scope of death doula practices, gender and professionalization, and the monetization of care-work. I present my findings in four sections to explore, first, how death doulas name and describe the work that they do; second, why the participants became death doulas; third, what skillsets they bring to their position; and fourth, their varying philosophies of care and the ways they configure gender in death doula work.

### **What's in a Name?: Death Doulas and Varying Titles**

Given that the death doula is a relatively new occupation and an unregulated profession, I set out to paint a fuller picture of death doulas and their roles, including the variation in titles they use and the services they offer. In particular, I wanted to gather data to determine whether death doulas are involved with bedside attendance and home funerals as Browne (2015) and Watson (2016) suggest. The data I collected suggests that the answer is no; death doulas are typically not present at the moment of death. With the exception of MacDonald who indicated

that she only provides services within the client's home, all of the participants stated that they provide their services in hospitals, homes, and hospices. That said, as the only participant who mentioned having frequently attended deaths, 15 to be exact, MacDonald did not specify whether these deaths occurred during her 15 years as an uncertified death doula or during the past three as a certified death doula.

As mentioned, in Canada, death doulas are not a regulated profession. As a result, there is much variation in the titles death doulas use and in the services they offer. For starters, the majority of the participants stated that they do not work full time as death doulas. In fact, from the demographic information and the interviews, I gather it is rare for a person to work full-time as a death doula. Instead, participants described working in a number of related occupations. For example, while noting in the demographic survey that her job is a "thanadoula," Lucy divulged in the interview that she also works in hospice care. MacDonald listed her occupation as the "business owner" of *Guiding Hand*, a place that "provide[s] professional compassionate services that inspire, empower and support communities to live well and die well" (Guiding Hand, n.d.). In addition, *Guiding Hand* offers First Aid and CPR courses, reiki, and Seniors' Help at Home, and has a shop where customers can purchase first aid kits and defibrillators.

For her part, Julie Keon, a forty-eight year old heterosexual Ontario woman, no longer refers to herself as a death doula. Instead, she identifies as a life-cycle celebrant. She defines a life-cycle celebrant as:

People who are trained in the art of creating ritual and ceremony, so I specialized in funerals and end-of-life rituals. But I am also a licensed marriage officiant. Most officiants don't have any training at all and celebrants actually learn the art and theory behind ceremony. I spent eight months studying to become a Life-Cycle Celebrant. It is

my profession. I create ceremonies for a living. I do funerals, marriages, and I have a baby blessing coming up. The people who seek me out are usually not religious because I'm not a minister. So big distinction. I mean some death doulas do 'rituals,' I suppose. But there's more to rituals and ceremonies than lighting candles... People think that doing physical rituals is what rituals are, but the ritual and the ceremony has to be meaningful for the people you are doing it for otherwise it doesn't make any sense.

Keon indicates above that she provides tailored ceremonial services for her clients. Implied in her description is the suggestion that she believes that death doulas typically do not engage with what she describes as personalized ritual making.

Keon, Nikolajev, and Jane all indicated that they also work as death educators. More specifically, Nikolajev works for Douglas College as an instructor for its end-of-life doula certification course. Jane works as an instructor at a location that will remain anonymous. Keon developed an independent, community-based course entitled "Ready Or Not!~ Preparing for the Inevitable" that explores practical preparations for one's own death and also tends to the emotional aspects of death and dying. The course costs \$175 to attend and Keon provides a sliding scale option for those who wish to attend but cannot afford the full cost. Interestingly, while not every individual who takes a certification course intends to become a death doula, it seems there are more individuals taking death doula certification courses than clients looking for death doulas. As Keon observed, "We're saturating a market that doesn't exist with this [death doulas]." In other words, despite the proliferation of training programs, there does not appear to be an equivalent demand for death doula services. While the other participants did not share Keon's exact views, there was a consensus among participants that the movement has been developing rapidly in recent years and it may be outpacing itself.

While many death doulas refer to themselves as “certified death doulas,” it is important to understand that while a death doula may have taken a training course, there is no standardization on what certification means, no agreed-upon core competencies, and no regulatory legislation. Additionally, as evident from the above discussion, there is no agreed-upon title for death doulas. These may seem like benign points; however, as a consequence of this variation in titles and the lack of a governing body, death doulas risk using incorrect language and terms or offering services that they legally cannot provide.

Take the experience of Tamara MacDonald. Macdonald is a fifty-one year old heterosexual woman who identifies as “Canadian.” She is the business owner of *Guiding Hand*, an organization that “provide[s] professional compassionate services that inspire, empower and support communities to live well and die well” (Guiding Hand, n.d.). Speaking directly to the issue of training, MacDonald recounts,

The one thing I would like to see happen with training is collaboration. When I say collaboration I mean that these death doula programs need to collaborate more so with other partners that are in the industry of death such as the funeral industry. I learned the hard way about what wording I could use and what wording I can't. I had the Attorney General call me. They said, “On your website it says you have ‘funeral planning’ listed, you can't use the word ‘funeral planning’ because it is owned by funeral directors. You can use ‘consulting’ or ‘facilitating’.” There are a lot of different things that need to be tweaked in this [death doula] movement and it is no fault of anyone's, it's just everyone needs to come together as a village and realize we can help each other.

MacDonald learned firsthand of the ways death doulas can unknowingly offer services or refer to themselves using titles they are not legally able to use. MacDonald calls for greater collaboration

between the providers of end-of-life care and funeral industries in order to avoid this confusion and strive for greater transparency. As a result, the various providers of funeral services and end-of-life care would be able to seamlessly connect and provide services without crossing into one another's boundaries. Arguably, MacDonald's statement provides a great piece of input for training programs, a point that I discuss in greater detail in Chapter 4.

Another significant aspect of the topic of reserved or 'protected' terms can be seen in the experiences of Pashta MaryMoon, a "death midwife" from British Columbia. MaryMoon is a sixty-seven year old woman who identifies as "Caucasian" and a "bi-lesbian, asexual."

MaryMoon has been providing end-of-life and death care in some capacity for over forty years, and only recently (in the past five years) has faced challenges in her chosen practice. In 2016, MaryMoon entered a legal battle with the College of Midwives of British Columbia (CMBC). She elaborates, "In the US, 'midwife' is not a reserved term. You can't reserve common speak, singular words. So of course, I was calling myself a death midwife long before I had any idea that in B.C. it is a reserved title." In our interview, MaryMoon argued that death midwives differ from death doulas because, in her view, death midwives such as herself provide 'pan-death' services that encompass pre-death, during death, and post-death support, "essentially combining the roles of death doula, home funeral guide, funeral celebrant." In her mind, death doulas primarily provide pre-death services such as advance care planning. She further explains that

We only use the term 'death midwife' in CINDEA<sup>10</sup> when it's pan-death in order to parallel the pan-birth of a birth midwife. You're doing pregnancy, labour, delivery... We felt it wasn't fair to use that term unless we were also giving pan services right across the spectrum.

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<sup>10</sup> Canadian Integrative Network for Death Education and Alternatives.

Here, MaryMoon finds parallels between midwifery and pan-death work, a comparison also made by other participants who often found their work similar to the work of birth doulas and midwives.

In 1995, the province of British Columbia established a *Midwives Regulation* section in its Health Professions Act (HPA). The new section defined midwifery as “the health profession in which a person provides services during normal pregnancy, labour, delivery and the post-partum period” (1995). It further stated, “The title ‘midwife’ is reserved for exclusive use by registrants” of this profession. Therefore, since MaryMoon is not a member of the CMBC and does not provide services to pregnant or labouring women, the CMBC argued that MaryMoon’s use of the term ‘midwife’ violated the HPA. However, B.C Supreme Court Justice Neena Sharma ruled HPA Section 12.1(1) to be unconstitutional, as it violated MaryMoon’s freedom of expression. While Sharma ruled in favour of MaryMoon, she also agreed with the CMBC that MaryMoon’s use of the term ‘death midwife’ violates the HPA (The Canadian Press, 2019). Despite these contradictory claims, in October 2019, Sharma ruled in MaryMoon’s favour, granting her the right to refer to herself as a death midwife (The Canadian Press, 2019).

Since this ruling, the CMBC filed an appeal and MaryMoon reported she is back in court fighting again for the title of death midwife. She explains,

Even if I lose the appeal, I’ll just have to find another word for somebody who offers pan-death services. It may just end up being pan-death doula or something like that. But, it’s not as clear to the public. If you say you’re a death midwife-- and I used to have a button that said ‘ask me what a death midwife is’ and the clerk would say ‘Death midwife? What’s that?’ And I’ll ask what they think it is. And they’ll sometimes ‘it’s sort



of like a birth midwife, you stay at home do what you want to. And do something similar with death?’ It’s very simplistic, but they kind of already get it.

As is apparent from this passage, MaryMoon’s connection to the term ‘midwife’ extends beyond applying the philosophy possessed by birth midwives to death midwives; the accessibility of language and terminology is equally important. MaryMoon wants her work to be easily understood and accessible to the public. Therefore, she chose to call herself a death ‘midwife,’ a term she believes the public would understand more intuitively than ‘doula.’ Moreover, MaryMoon’s situation speaks to what counts as death reform in Canada. Though MaryMoon does not frame her court case as activism under traditional terms, since her court case effectively broadened the scope of midwifery to include death work, it could be argued that her case falls under the broad umbrella of death activism.

While MaryMoon and the participants at large seem to stress the importance of accessibility with their terminology in order to demystify death, it is ironic that the vague descriptors they use to describe their various roles do not concretely communicate what it is that death doulas do for their clients. As became evident through the interviews, some of these roles do become more defined. For instance, for Keon and MacDonald, “education” surrounding the one’s right to die at home and to keep the body at home appeared to be very important for families of palliative children. However, other roles remain vague.

Other participants also observed a lack of public knowledge about death doulas’ roles and services. For example, one major misconception is the assumption that death doulas are only involved at the end of life. As MacDonald stated:

No one wants to talk about death. When someone is dying and they decide to call a death doula, even the word scares them. In my business, what I do is support people prior to the

end of life. I am doing services to build a relationship prior to the end of life. And then when death comes it is easier for them to have those conversations with me because they trust me.

Here MacDonald asserts that in general, her work is important before one gets to the end of life precisely because conversations about death are so difficult. As such, she stresses that her role in building a relationship with her clients is important long before death is imminent. In this case, MacDonald implies that establishing trust is important in order to have meaningful difficult conversations with her clients.

The words of Jane, a fifty-year-old woman from Saskatchewan who identifies as Caucasian, operate along similar lines. She states,

I think there is a misconception that an end-of-life doula is only at the time of death.

Where we're actually brought in way before, sometimes we are brought in before someone might have a life limiting illness. Some people are seeing us about their plans or preparations.

The above quotes indicate that the assumptions embedded in the name “death doula” or “end-of-life doula” influence how the public perceives their roles and functions. MacDonald suggests that cultural death phobia impacts how individuals view death doulas, as the inclusion of the word “death” is enough to elicit fear. Jane, meanwhile, observes that her work generally starts much earlier. Both indicate that they are involved in relationships, planning, and preparation, work that starts well before “end of life” itself.

These findings are consistent with Bales, Gale, and Kagan’s (2004) suggestion that doula models of care often focus on developing close relationships with clients in order to meet often neglected emotional needs (p. 40). In fact, emotional support and trust seem central to how

MacDonald and Jane conceptualize the roles of a death doula, which in turn speaks to the importance of emotional bonds in gendered understandings of care-work. In Thory's (2013) analysis on the gendered nature of emotional intelligence in the workplace, for example, she describes emotional intelligence as the "ability to perceive, use, understand, and manage emotions in one's self and others" (p. 222). The management of emotion and the use of bonding emotionally with clients (a tactic Thory observes is often associated with women) appears central to the role of the death doula. The establishment of a "therapeutic relationship," a term in nursing that refers to the professional boundaries nurses establish with their patients (Virani et. al., 2002), between the death doula and the client has emerged as a sub-theme that enables their work of planning, assistance, and emotional support to be effectively completed; when trust is created these actions can then proceed. While MacDonald shared with me that she completed a course on Grief and Bereavement Support at the University of Toronto to better support her clients, death doulas are not required to seek formal training in grief and bereavement. That is, because death doulas are an unregulated profession, there are no professional standards of practice or core competencies to guide the therapeutic relationship aspects of death doula practice.

As a profession that appears to be most common amongst women, the role of gender is central to how many of the participants framed the doula-client relationship and emotionality in their line of work. For this reason, it is important to look deeper into the gendered logics embedded in death doula circles as it was often at play when the participants discussed the skills necessary to be successful as a death doula.

### **Innate or "Natural" Skills to Support Death**

One of the first questions I asked in the interviews was "Why did you decide to become a death doula?" The question prompted insights into how the participants became interested in this

field of work, and into how they framed what they often described as a “calling” to become death doulas in relation to gender. A number of the participants indicated that they possessed innate or natural knowledge and skills that suited them for death doula work. For example, Olga Nikolajev, a forty-nine year old woman of undisclosed race and sexuality who works as a nurse, death educator, and death doula indicated:

I always had the qualities to support people through transition and through change, I think I’m fundamentally a person who holds a positive mood and a non-judgemental stance. And so, it maybe in some sense comes naturally. I am also a person who likes change and also wants to engage with change.

In this quote, Nikolajev speaks to possessing supportive, non-judgemental qualities that naturally enable her to be successful as a death doula. Taken alone, the qualities Nikolajev listed do not specifically relate to gendered conceptions of the self. However, she elaborates that in the field of death doula work, “There are conversations. Is it a calling? There are some patterns. Most of the end-of-life doulas, death doulas, those who want to engage in conversations about death and loss are primarily women, around the age of fifty.” Here, Nikolajev identifies middle-aged women as individuals who most often become a death doula. She elaborates:

It’s that transition time for a woman, going through it myself, how do I transition into the period of my life where... Where are my children going to be? Where are the changes happening in my physical body? Nobody told me about all those changes. My mother didn’t tell me about those changes. And there are some emotional, physical, spiritual – whatever -- you call it... It comes to how you come to understand death as a potential for perspective.

In this statement, Nikolajev associates middle age as time of change, where one's children are potentially growing up and they may be experiencing bodily changes themselves as they age.

She identifies this as the age in particular where death becomes a “potential for perspective.”

Nikolajev further aligns death doula work with normative cisgender womanhood, stating,

Women I think intuitively know how to hold a space for change. Because we have to deal with it. I don't have any children, but I can imagine that through a women's lifetime—though it has changed recently—women far more often go through the changes of death. We ingest the unjust of the world as spiritual beings into our womb space of transformation and we slough off that which isn't needed.

In other words, Nikolajev aligns cisgender women, specifically their biological processes, to intuitive understandings that make them well suited to death care, since as she argues, women “more often go through the changes of death.” This is a highly gendered understanding that frames women as inherently suited to care-work, specifically due to a “womb space of transformation.” While Nikolajev may not have intended her comment to be exclusionary, one could read this as a biologically essentialist statement that excludes men, transgender, non-binary, and gender non-conforming individuals from being valid or “intuitive” providers of care-work.

Several participants mentioned that prior experiences with death made them realize they had skills that would be well suited to death doula work. When I asked Lucy, MacDonald and MaryMoon why they became death doulas, they provided examples of personal experiences that led them towards becoming a death doula. Lucy, a fifty-year-old heterosexual woman who identifies as “Italian Canadian” and works as a thanadoula, noted that,

It was after I saw how my friend was treated at the hospital. I thought, there has to be a better way than this... And her kids didn't know what to do. I didn't know where I could fit in and where I could offer comfort because that's a very—kind of sacred space... It was because of her that I thought we have to do things differently because she wasn't taken care of. No fault of the hospital, it is... They don't have the manpower for that. They don't have the training. It's done differently there.

What Lucy points to is the perception that the hospital environment did not adequately support her friend and her friend's children during her friend's death. I wonder if Lucy's experience relates to her suggestion that professionalization would make death doula work “less caring and nurturing,” a suggestion I discuss in more detail in Chapter 4. After all, if Lucy felt the hospital was not adequately addressing her friend's (and her friend's family's) emotional needs, she might also assume that professionalized medical environments are impersonal.

For her part, MacDonald recounts a childhood experience as the impetus for her work, as well as other, more recent, family experiences with death and dying:

I truly feel I didn't choose to be a death doula, that it chose me. I had a nephew who died of crib death and I remember the situation now looking back, I was very intrigued in what was going on. At ten years old I wanted to know more. Why were my grandparents upset? Why was there shame? Why were us kids shunned from the room? A lot of different components at that age triggered me to want to know more... Then when I was twenty years old, I was faced with my grandfather who was diagnosed with cancer... I sold everything I had and moved in with him to take care of him. Then it just started to snowball from there. My nephew was diagnosed with leukemia, my sister asked me to

move in with her and to help him die at home. There was just so many times I was a death doula and didn't know.

What is striking about MacDonald's comments is that she believes that her sustained connections with death in her family created the conditions for her to be identified and "chosen" as a death doula. These examples reflect a pattern of those who decided to become death doulas: They often believe they possess innate qualities that led them to becoming successful death doulas.

When I asked her why she became a death doula, MaryMoon took a similar position to Lucy and MacDonald, stating,

It's sort of been with me all my life. The original story I tell was being seven years old, watching TV when I wasn't supposed to. I was sitting right in front of the TV, watching an old cowboys and Indians movie of the '50s. Pioneer family goes out, Indians quote "come in" kill the husband, leave. Wife has no choice but clean him up and bury him.

And I walked away from the movie thinking that makes more sense.

In other words, MaryMoon's experience as a child witnessing a historic imagining of a funeral from a Western movie from the 1950s "made more sense" than her contemporary experience with funerals at the time. What I gather from MaryMoon's comments is that her experience watching a wife prepare her dead husband for burial appeared to be more personable and potentially more caring than professional funeral directors, whose practices might be perceived as clinical, distant, and not welcoming of familial participation in death rituals. However, associating the role of death doulas in alternative death care with preindustrial funeral traditions may have unintended consequences. Such an association risks conflating women-identified individuals as ideal caregivers of the dead and dying since, historically speaking, the burden of care most often fell to women (Habenstein & Lamers, 1990; Rundblad, 1995).

In their responses, Lucy, MacDonald and MaryMoon relayed personal stories that set them on the path towards death doula work. Outside of connections to gender and care-work, their responses also reveal larger insights into how Canadians interact with the subject of death and death care in Canada. Lucy, for example, indicates a sense of dissatisfaction with the experience of witnessing her friend die at the hospital. As indicated in the literature about doula work, many scholars reported that their participants became doulas due to perceived gaps in current models of care. Lucy's quote exemplifies the feelings of loss and lack of control that have been echoed by families who have experienced the death of a family member in the hospital, thus following the patterns of individuals encountering a gap in the healthcare system and taking steps to apply doula models of care to provide additional support.

Moreover, MacDonald's quote provides an example of the culture of silence that has emerged around death in Canada, a silence that may be connected to patriarchal values of stoicism in professionalized environments (Hearn, 1982). What is particularly interesting is that MacDonald highlights the tendency of adults to shut children out of conversations about death, which has the potential of preventing children from processing grief in a healthy way. While the subject of caring for families of palliative and deceased children emerged during the interviews, less explored were the ways death-phobia impacts children and teenagers. This is a subject I believe deserves future research consideration in order to better understand the ways young people can engage with death, grief, and loss in a productive and healthy way.

### **“Stay in Your Own Lane”: The Scope of Death Doula Practices**

Out of the six participants, three had previously worked or are continuing to work in a medical field. For example, Nikolajev works as a nurse, Lucy works in a hospice providing



palliative massage, and Keon has prior experience working as a birth doula. When I asked the participants about this pattern, Jane and Nikolajev confirmed that many individuals taking end-of-life doula training courses have a medical background, and while many of them do not intend to become death doulas, they are interested in supplementing their own knowledge. In addition to students with medical backgrounds, Jane also found that “mediums, psychic mediums and spiritual people have shown up in the classroom as well.”

All of this being said, the death doulas I interviewed consistently emphasised that their role was to provide non-medical support, empower families, and act as a supportive person to the dying individual and/or their family and loved ones. However, there were some notable differences. MaryMoon provides pan-death (pre-death planning, bedside assistance, and post-death support) services for her clients, while Lucy emphasizes the spiritual aspects of her work. Lucy specified that when she began practicing as a death doula, she was involved in New Age spirituality. She is now exploring the possibility of providing services catered to Christian communities. Additionally, while Lucy does not identify as a death midwife, she was the only death doula to state that she is trained to facilitate home funerals. However, she does not advertise that particular service to her clients on her website.

While death doulas have long been understood as adjacent to the home funeral movement, it is important for potential clients to know that death doulas are not legally capable of facilitating home funeral services in Ontario, Saskatchewan, and British Columbia, the provinces where my participants reside. According to the Bereavement Authority of Ontario, for example, “Family members can legally provide funeral services without a license [but] . . . cannot be paid for this service” (A Guide to Death Care in Ontario, 2002). This statement clarifies that family members can legally conduct funeral services for their deceased; however,

they cannot receive remuneration for the service. Only a licenced funeral director can be paid for providing services at a home funeral. A majority of the participants were aware of this legislation. As MacDonald indicated, “as a death doula, we do not facilitate the whole home funeral... It is important to understand that to provide services of a home funeral you do need to work with a licensed funeral director.” However, when Keon was shadowing the current instructor of a death doula-training program she was invited to teach at, she witnessed the following:

The instructor said to the group, “Why do you think you’re not allowed to touch the body as a death doula?” And she said, “Because of disease and bacteria, and communicable diseases you might not be aware of.” And I was like... “No! Because it’s against the law! It’s against the law in Ontario, that’s why!” To me it is a basic law. That’s why death doulas don’t handle the body, because then you’re crossing the line into licensed funeral director territory.

There are a few comments in Keon’s statement that warrant clarification. Firstly, Keon is correct in her claim that bacteria and communicable diseases are not the reason why death doulas are not legally allowed to touch the body. Generally speaking, corpses are not dangerous and it is a myth that individuals can become sick after being in contact with a dead body. As Eberwine (2005) explains,

The microorganisms that are involved in decomposition are not the kind that cause disease.... And most viruses and bacteria that do cause disease cannot survive more than a few hours in a dead body. An apparent exception is the human immunodeficiency virus, HIV, which has been shown to live up to 16 days in a corpse under refrigeration. (p. 4)

While HIV can survive in a corpse for up to 16 days, it should be noted that a dead person who has contracted HIV is no more dangerous than a living person with HIV. As Dr Sathyavagiswaran M.D, a pathologist and chief medical examiner-coroner for the County of Los Angeles, explains,

There is no reason that an unembalmed dead human body should be infectious to anyone attending visitation or public services. Persons transporting and handling bodies or cutting into them may be vulnerable in rare instances, with little or no risk if proper precautions are taken. To refuse to present a body unembalmed because of public health risk is unfounded.... Riding on an airplane or a bus may be a public health risk; the presence of an un-embalmed body is not. (as cited in Hast, 2006, p. 2)

In a letter provided by the Funeral Consumers Alliance, an organization that monitors the American funeral industry and advocates for fair practices for consumers, epidemiologist Osterholm wrote to Representative Carolyn Laines (2010) regarding a bill that would change Minnesota's provisions related to viewing and transporting dead bodies. On the subject of whether bodies are dangerous after death, he said,

the mere presence of a dead body without regard to its embalmed status and one that is not leaking blood from an open wound or perforation, does not pose any increased risk of infectious disease transmission for the person who might handle that body or review it in a private setting. Once a human dies, infectious agents that would be of any concern, including those on the individual's skin or internal organs is greatly diminished. The lack of risk of infectious disease transmission in the handling of a dead human body without incisions or perforations is obvious when one realizes that today many dying individuals receive hospice care in their own home from family and loved ones without healthcare

training and without measurable infectious disease risk to these same persons. To now suggest that somehow the death of that individual makes that body a new and major infectious disease concern is simply without scientific merit. (para. 3)

Having addressed the myth that dead bodies are highly infectious carriers of disease, I will now return to Keon's statement. To reiterate, it is not against the law for death doulas to handle the body due to the presence of communicable diseases in the corpse, but rather, it is against the law for anyone except for funeral professionals to handle the body in exchange for money. The laws Keon cites are located in Ontario's *Funeral, Burial and Cremation Services Act* (2002) and are also relayed to consumers in a Consumer Information Guide from the Bereavement Authority of Ontario (2019). As stated in the Introduction, there are similar laws in place that forbid all except funeral professionals from accepting payment for facilitating home funerals or preparing a body. These laws exist in order to ensure bodies are treated with dignity and that bodies are interred safely. While families are allowed to facilitate their own home funeral and prepare the body, generally speaking families work with funeral directors and/or cemeteries to arrange burial or cremation.

A lack of consensus among death doulas about the nature of their work and about the provision of home funerals is likely the reason for the confusion and may speak to broader societal views of death and dead bodies. For death doulas specifically however, much of the misinformation appears to stem from death doula training programs, a subject I discuss in the next chapter. While I do not delve too deep into the subject of training programs in the context of this thesis, I believe it is important for the reader and for potential death doula clients to be aware of relevant legal risks pertaining to the subject of home funerals and the variance between death doula services.

In discussing the legal aspects of death doula's roles and responsibilities, the participants stressed that they only provided non-medical support for clients. As Keon stated, "We're not doing anything medical if you're working in your scope of practice. I think people can do the volunteer hospice training and read some really good books about death doula skills then put those skills to practice." In this statement, Keon explains that there is potential for obtaining non-commodified training by professionals. Lucy goes a step further to describe the non-medical roles death doulas can occupy. She said,

Perhaps we can help be a mediator to their loved ones, or to their medical team. We could possibly do massage or music, or do something to help tweak the setting to make it more homey. We can offer respite care, take the burden off their family. There's so many more things we can do.

The roles Lucy and Keon describe fall under the umbrella of non-medical support, including respite care, mediation between funeral and health care providers, and pre-planning one's affairs prior to death. Lucy also made it clear that this form of care encompasses a broad range of activities, including playing music and providing personal touches that may make their space in hospice or in hospital more comfortable.

Of the participants, MacDonald was the most vocal about death doulas remaining inside their scope of practice. As she stated, "I'll use this word a lot, 'stay in your own lane,' because it is imperative as a death doula that you do not cross. You stay in your own skillset and you do not try to be anyone else. You walk alongside the medical team." MacDonald's appeal for death doulas to "stay in their own lane" was due to her concern about what she perceived as unprofessional conduct that could raise concerns among medical professionals about the credibility and consistency of death doulas. She explained,

Once we are regulated the medical professionals will understand what it is we do, know that we are regulated, and that we are not crossing over into what they do. They will know that we are being monitored and that is very important to build relationships. One of my mentors is one of the head palliative care educators in my region and we talk about this all the time. Her big fear—she would love to have death doulas in hospice, in hospitals—but her big fear is that she has met many death doulas who don't necessarily stay in their own lane. They will say, "Oh they have you on that medication? Oh that's a little bit too strong." How do you know that? You're not a doctor! So stay in your own lane as a death doula and that will help all of us progress in the future.

What MacDonald is speaking to here are experiences with death doulas who step outside of their scope of practice to provide unqualified medical advice. MacDonald looks to these experiences as evidence to explain why death doulas are not taken seriously by medical professionals. What I gather from this quote, and study more broadly, is that there is so much variance amongst death doulas that, in general, death doulas may not know what their scope of practice is. The ramifications of not having a coherent scope of practice speak to what I view as inconsistencies in death doula practices.

Lucy provides an example of a death doula "not staying in their own lane." Lucy diverges from MacDonald, however, in framing the intervention of her death doula friend as a positive aspect of death doula work rather than a moment of stepping beyond her scope of practice. Lucy said,

My one girlfriend, she has a pharmaceutical background. Been selling oncology drugs for thirty years, so she really knows medication. Her niche is going into the cancer

appointments with you and judging if chemotherapy or radiation is truly beneficial, because, what will your quality of life be after?

While Lucy brings attention to an important conversation about the occurrences of medical providers approaching clients with aggressive treatments without consideration as to whether it will improve their quality of life, I would like to focus on another element of this statement: Is it within the scope of practice of a death doula to question medical treatments? If MacDonald is correct in her claim that death doulas frequently step outside their role to provide unqualified medical advice, then there is a potential of harm and risk (physical, emotional, legal) to both death doulas and their clients. For example, a death doula could potentially undermine the trust a client has in their doctor thereby altering their relationship, which will affect overall care; or, a death doula could be blamed if something were to go wrong if a patient were to follow through on their medical advice, risking reputation and potential legal actions.

Of all the participants, Keon was the most critical of the role of death doulas in general. Keon's concern about what she terms "the imbalance of ego and integrity" within death doula communities is complex and spreads through multiple themes, including monetization, training, cultural appropriation, and scope of practice. During the interview, Keon drew my attention to death doula organizing online (associations, Facebook groups, forums) and the growing trendiness of death doula work. She explained:

I think what I see in this death doula movement is an imbalance of ego and integrity.

There're a lot of people that say: "I want to be a death doula! How do I become a death doula? What training do I need to take?" And I saw a thread recently, of "I think there should be a specialty of death doulas who work with families that have children who are dying," and then all these people were like "I wanna work with dying children!" And I

was like, this is so bizarre... It's something I've been struggling with and I actually struggle with identifying as a death doula because of the trendiness of it.

Here, Keon expresses a discomfort with identifying as a death doula due to the trendiness and apparent lack of professionalism surrounding the occupation. What I gather from these statements is that Keon feels alienated by what she perceives as unprofessional online conduct, where dying children are exoticized and specifically targeted as a group that death doulas should service. As a mother of a child "who is palliative," Keon explained that

I have a connection with that community already, which is why my hairs stand up on the back of my neck when people go 'I want to work with dying children!' Some of us live that reality and it's not a novelty. I had a death doula trainer tell me that I was lucky because I had my foot in the door.

What stands out to me in this statement is Keon's assessment of the lack of tact or sensitivity on the part of some death doulas to the emotional realities of their potential clients. In other words, in their pursuit to provide emotional support, death doulas may offend, however unintentionally, those clients and families who may be feeling distressing emotions related to grief and loss. This leads me to ask if death doulas, as an unregulated profession with undefined training curriculums and undefined entry-level competencies, run the risk of offering services that lack a professional standard.

### **Gender and the Question of Professionalization**

Participants often coupled their perceptions of their roles as death doulas with their perceptions of midwifery, a profession they viewed as having a similar scope of practice and potential trajectory to death doula work. In Canada, midwives underwent a process of professionalization during the last decades of the twentieth century and the first decade of the



twenty-first century. The professionalization of the midwife looms large in the imaginations of many of the participants, mainly as a warning of what could come for death doulas. On this subject, Nikolajev asked:

Why are we arguing about the professionalization of knowledge that really needs to be social? And in some ways is engrained in every person? I think there is something in each and every one of us that if we are present with or are forced to be present with dying I think we will find a way within ourselves to do that. I think there's a way. I think we innately have that. In the same way women have an innate way of how a baby comes out and what they have to do, we are now coming to that realization?

Here Nikolajev suggests that death, like birth, is a natural non-medicalized event and the knowledge associated with caring for the dying is not a specialized skill, but rather knowledge that all people innately possess.

As we saw in the case of MaryMoon's use of the term death midwife, the parallel between birth and death emerged frequently with many of the participants. However, while the subject of the medicalization of birth and death is important, it is equally important to be wary of the essentializing statements contained within these parallels, especially about gender and biological processes. For example, I see in Nikolajev's statement parallels to birth doula discourse in which the essentialization of "natural birth" is rampant. In fact, the "alternate birth movement" has been critiqued by many for over-simplifying, and countering a male-dominated medical system with discourses that situate women as naturally empathetic caregivers (Dillaway & Brubaker 2006; Johnson 2008). In Western nations, where there is greater access to sanitary locations in which to give birth, white, middle-class women are more able to reject medicalization in relative safety. The assertion that natural births with midwives is a superior,

more holistic way to give birth and that bodies “just know what to do” during birth are statements made from a privileged position as they exclude and potentially alienate women who experience difficult and traumatizing births (Johnson 2008). Read in this light, Nikolajev’s suggestion that death is always natural, innate, or peaceful excludes traumatizing experiences with death. Nikolajev’s comments suggest that, for her, death doula work exists within an essentialist framework, whereby biological processes and “innate” understandings of death are conflated with one another under a model of highly gendered care-work.

Prior to divulging the details about her training in facilitating home funerals, Lucy shared her reservations about contemporary death doula training programs and in so doing connected the threads of gendered care-work and monetization. She said:

Now here’s my concern. You can become a death doula in four hours. You want to be a death doula? Take this weekend course. Then go work with dying people. I worry about it. Not that... I mean you learn while on the job. And I look at it like, I’m a daughter for hire. I am your end-of-life companion, so you’re not alone. Maybe I can be a mediator between you, your family and loved ones, or with staff, maybe I can help get the right people in place... I guess another obstacle would be we are all trained.

Here Lucy expresses her fears about unqualified students becoming death doulas in “less than four hours” while simultaneously reflecting on how training itself could also be an obstacle. It should be noted that the relatively short training period for death doulas is not unusual; basic labour doula training can be completed in a weekend as well (Birth Mark – Labour Doula Training, 2020).

However, what is important about this exchange is how Lucy views herself as a “daughter for hire.” What is an ideal daughter if not someone who is devoted and selfless? In this

statement, Lucy places herself in an intimate role in a family's life, one that is gendered and placed within a familial hierarchy. Interestingly, Lucy frames the personable role of a daughter to a position that is hireable, thus drawing a connection to gendered care-work and monetization.

When I asked Lucy if she believed death doulas should be regulated, she said:

No, I don't. Because I think you're going to limit people and they are not going to do what they are supposed to be doing. Right? Having a vulnerable sector check, being insured, having things like that. I think that's important. But I don't want Big Brother to come down and tell me what I can and cannot do. I think to be safe and everything like that... I don't want them to come in and take over something that is nurturing and caring because that's when things can become less caring and less nurturing. I see what the hospitals are regulated for—Oh my gosh! It's like, brutal what they can and cannot do.

As an end of life companion, I wouldn't want someone to say you can't do this.

Similar to arguments made against the professionalization of midwifery, Lucy's stance against regulation is primarily about not wanting to be limited in what she can and cannot do with clients. For Lucy, the lack of regulation enables her to practice without "having her hands tied" or "being told what to do." Lucy does not want death doula work to be professionalized because she does not want "them [professionals] to come in and take over something that is nurturing and caring because that's when things can become less caring and less nurturing." Interesting here is that Lucy repeats the words "caring" and "nurturing," and in this way stresses that she associates her work with normatively feminine qualities. Further, Lucy understands death doula work as "a calling" and states that she did not expect to "buy a Mercedes or anything." It appears that for Lucy, altruistic care is central to death doula work and she does not want structures in place that could hinder or limit the work she does.

Echoing Lucy's concern, Hearn (1982), argues, "Within nursing, health visiting, midwifery, social work and teaching are the emerging structure by which grief, joy, loss and despair are patriarchally socialized... Activities and experiences formerly performed privately or controlled by women became in this way brought into public control by men, and so subject to the expertise of experts" (p. 191). Hearn claims that emotional care primarily associated with and conducted by women is not welcome in professional settings. Instead, care-work becomes medicalized, rigid, and impersonal within professionalized fields. Hearn's analysis seems to be the logic underlying participant stances against professionalization. It appears that they find freedom to engage with their clients in frank, often emotional discussions in ways they believe would not be possible if they were a regulated profession.

Financial concerns, particularly as they relate to discourses of gendered care-work, emerge in complex ways in the interviews. While Jane and Keon state that death doulas should not be expected to be "martyrs" offering their services for free, they are also concerned about profit-making in death doula circles. Though care-work is a notoriously under-paid and gendered form of labour, participants expressed concern about capitalising and exploiting grief for payment. As Jane indicated:

There is a tension around charging for services and fees. That sat with me while I was learning. My first year I was learning, I volunteered and offered my services for free. But it came to a position where I was hiring babysitters and paying out of pocket to be with those who are dying, and my gas money, etcetera. I got to a point where I would love to but that just isn't reality... I have a sliding scale and I wouldn't be able to turn somebody away because they can't afford. I've worked out exchanges, like I've worked out an exchange where I received a massage, or tickets to the opera. One of my clients who is a

tutor, she says “I get paid forty five dollars an hour to tutor people, would you be able to accept that?” And I’m like, “sure.”

These statements exemplify the conflict between charging for one’s services and providing unwaged, altruistic care, a tension that exists due to gendered norms around caregiving. This disconnect is reminiscent of what Hochschild refers to as the “third sector of social life” (cited in Stacey & Ayers, 2011, p. 47). In Stacey and Ayers’ (2011) study into the experiences of family homecare providers, they find that care-workers struggle to make sense of their care-work, simultaneously believing that care-labour should not be exchanged for pay but also recognizing their own economic realities and their need to be paid. In their words, “Caregivers perceive waged care as a violation of social norms surrounding family care, namely that care should not be exchanged for pay” (Stacey & Ayers, 2011, p. 48). Similar to the tension raised by the participants, Stacey and Ayers found that caregivers manage the norm violation by framing their labour as altruistically motivated and valuable for their employers, and society at large (p. 48).

These feelings of obligation to volunteer or provide unwaged work might emerge because it likely does not feel good to charge those experiencing emotional devastation, or perhaps because women are socialized to not attach high monetary values to their labour. Keon stated as much, observing,

I think it is our responsibility if we are doing end-of-life care that you do community service. If a person can’t afford it you do it yourself, or work with a group of doulas. This is where it gets tricky, because people shouldn’t be expected to be martyrs. I can’t afford to commit 50 hours to somebody pro bono and miss out on work where I get paid, because I still have to eat and pay bills.

In this quote, Keon reveals her belief in the responsibility of death doulas to do community service and indicates that teamwork and collaboration with other death doulas could help enable death doulas to volunteer more of their services. However, Keon also recognizes that she cannot commit that much of her time to pro bono work as she has to, in her words, “eat and pay bills.”

The moral economies of waged care-work are present as an undercurrent through many of the interviews. As exemplified in the quotes from Jane and Keon above, many of the participants expressed the belief that those who work in end-of-life care should be committed to community service. Yet, they are also mindful of the simultaneous reality that death doulas still have bills to pay, their own families to care for, and in many cases their primary job to attend to. Overall, the results concerning altruistic motivations for care-work are consistent with Stacey and Ayers’ (2011) findings. Just as Lucy believes that regulation will make death doula work “less caring and nurturing,” the language with which many of the participants articulate their role as a death doula is highly gendered and coupled with suggestions that they work in this field because they are naturally caring (women) individuals.

### **Conclusion**

In this chapter, I explored the theme of care-work and gender in relation to death doula practices. As MaryMoon suggests, the death reform movement appears to be striving for a more economical, hands-on version of end-of-life and funeral care; however, despite participant fears about the proliferation of training courses, death doulas may be capitalizing on death in the very way they are trying to avoid. In discussing five major sub-themes -- namely, the implications of language, innate knowledge and skills, scope of practice, gender and professionalization, and monetization of care-work -- I showed how participants frequently frame their roles as death doulas in relation to hegemonic understandings of gender. Moreover, I suggested that having a

lack of regulation contributes to an undefined scope of practice and professional standards, which may contribute to a lack of cohesiveness among the participants. What are the potentially wide-reaching consequences of this lack of cohesiveness in terms of the growth, credibility and accountability of the profession and its practitioners? I turn to this and related questions in the next chapter.

## **CHAPTER 4: THE PROJECT OF DEATH REFORM: DEATH POSITIVITY, COMMODIFICATION, AND EDUCATION**

Presently, there are multiple calls to “reform” end-of-life and funeral care in North America in order to revolutionize not only how Western societies engage with death, but also how they organize the systems that manage death. The growing interest in the death positive movement by the general public, as indicated by the sudden growth in newspaper articles about death positivity and increased popularity in social events such as Death Cafés, indicates that there is an increasing willingness to challenge death as a taboo subject in the public sphere. The scholarly literature and terminology that surrounds the modern exploration of death in North America is often grouped under what has been termed the “death positive movement.” However, individuals who want to see systemic changes in end-of-life and funeral care and whose opinions are often described as “death positive,” might not see their work as such. For this reason, I suggest that the field of Death Studies may take a monolithic frame and lack critical engagement with some of what it means to be associated with death positivity.

As noted in my literature review, much of the extant death studies literature identifies death doula as potential allies or proponents of death positivity. This is due to what appear to be aligning interests and philosophies. Many scholars speak of death positivity in overwhelmingly positive terms, including Booth (2019), who suggests that death positivity is a “life changer”. However, is there room for dissent? Many of the participants in this study identified the death positive movement as an uncomfortable association despite their apparent congruent belief systems. In this chapter, I outline the overlaps between three interrelated subjects: participant perceptions of the death positive movement, their thoughts about the commodification of death and how commodification relates to death doula training and education. In particular, I consider



the links between the potential commodification of the death positive movement and the death doula movement (both are often seen as activist movements) and the commodification of a growing interest in death doula work through training programs.

### **Doulas on Death Reform: The Death Positive Movement Revisited**

In popular media, death doulas are often located as participants in the death positive movement.<sup>11</sup> Proponents of death positivity believe,

That by hiding death and dying behind closed doors we do more harm than good to our society... that the laws that govern death, dying and end-of-life care should ensure that a person's wishes are honored, regardless of sexual, gender, racial or religious identity... and that the dead body is not dangerous, and that everyone should be empowered (should they wish to be) to be involved in care for their own dead. (The Order of the Good Death, n.d., para. 2)

This statement contains many of the key tenets of the death positive philosophy. Essentially, proponents of death positivity believe that hegemonic models of end-of-life and funeral care do not acknowledge the feelings associated with death and hide the experience of death from view, thus leaving individuals feeling emotionally unfulfilled or alienated from the processes of grief. There is also an acknowledgement in death positivity that experiences of death are not monolithic and can be influenced by systemic inequalities. Death doulas are often associated with and appear to have similar philosophies to those expressed in the death positive movement. For instance, Booth (2019) identifies death doulas as individuals who are “rebranding” death and

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<sup>11</sup> For further information on the death positive movement please refer to the introduction

in his article “The Positive Death Movement Comes to Life,” Leland (2018) further connects death doulas to death positivity.

Some of the death doulas I interviewed espoused views that some would associate with death positivity. The following statement by MaryMoon is an example of just such a death doula philosophy: “Part of what we were trying to do was get it back in people’s hands, make it more economical than traditional death stuff is, you know the whole pan-death process... Make it more hands on, make it more personalized, etcetera.” This statement illustrates that MaryMoon’s understanding of the death doula movement appears to be rooted in resisting the commodification of hegemonic death care, a motivation that the death positive movement would also share. However, some death doulas appear to see themselves as part of a movement outside of the death positive movement. Jane in particular refers to the “community deathcare movement,” which she describes as,

A huge umbrella, a huge movement and within that movement there are different approaches. We are trained [in the community death care movement] to be non-judgemental, non-biased, open minded, not have your own agenda to understand that we can reclaim and be close to the dying process. And although we teach that, there is still a lot of judgement within our own community of who can do it, who can’t.

While Jane describes the community deathcare movement as a “huge umbrella” it is important to note that it is not as large or as prolific as the death positive movement. As an important part of this movement, Community Death Care Canada describes itself as an “an emerging non-profit group, coming together in response to the needs and interests of Canadians who seek to re-engage with dying and death care in more meaningful, holistic, and environmentally sustainable ways” (Community Death Care Canada, n.d.). While Jane stated that she personally does not

identify with death positivity, she does consider herself a part of the community death care movement, which she describes as including many different approaches. As such, it is important to stress the potential for overlap, as there may be members of the community death care movement who are also proponents of death positivity.

In addition, the death doulas I interviewed and proponents of the death positive movement seem to share similar views about particular traditions modelled on pre-Industrialized, hegemonic American understandings of end-of-life and funeral care; as both parties call for a return to non-polluting, hands-on, end-of-life and funeral practices. As Lucy noted:

We learned how to wash the body—how to guide the family to wash the body, how to keep the body cold for three days. Something that was done freely before the Civil War— We didn't start embalming bodies until the Civil War, when they were bringing soldiers back home that they were decaying. So, they would fill them with arsenic and send them back home. Up until then, people had their funerals in their parlour, that was what they were there for, the living room and all that stuff. I'd like to see that come back, I really would.

MaryMoon elaborated on a similar point, if taking a slightly different stance. She stated,

There are a lot of people who assume that eventually we will get to this place where families do it all by themselves and we don't need death doulas, death midwives, home funeral guides etcetera. I don't think we are ever going to get there... People took care of their own dead up until the 20th century, they lived in farming communities where they were dealing with the death of their livestock, death was all over the place... We are not going to go back there. That's just the reality. We are too urbanized, and we will continue to be too urbanized. I think that, personally, I think that if a family feels comfortable

doing it themselves, great! But in most cases they are going to want a guide, someone who can support them, make sure they are doing things right, bring up suggestions that never would have occurred to them.

What is significant about these statements is their reference to an idealized understanding of “history,” and a striving to return to “old ways” without the intervention of professionals or medicalized practices. In particular, the “old ways” of end-of-life and funeral care are reminiscent of Rundblad’s (1995) account of the shrouding women, who were the primary caretakers of the dead and dying in America prior to the professionalization of the funeral industry at the end of the nineteenth century.

It is also worth noting that MaryMoon’s belief that Canada is “too urbanized” negates the experiences of those living in isolated, rural communities, many of whom do not have access to the end-of-life care they desire and need. At the present time, the community based death practices called for by the alternative death movement, the community death care movement and the death positive movement are still not easily accessible unless one is privileged enough to pay for at-home services. The suggestion of returning death and end-of-life care to the home is thus not realistic for the vast majority of Canadians. While studies have consistently shown that there is value and satisfaction in at-home end-of-life care (Tanuseputro et al. 2018, Fowler & Hammer 2013, Bluebond-Langer et al. 2013, Gao et al 2013), there are currently not enough measures in place for Canadians to receive palliative care at home. Nor are many Canadians able to pay for private services within their home (Arnup, 2018).

As implied above, I read these participant calls for a particular brand of death reform as rooted in Eurocentric traditions; the narratives participants align themselves with are not mindful of class-based distinctions or non-European funerary practices. For example, Lucy’s description

of funerary techniques in Civil War era America were hardly universal; even among the Europeans she describes, not every family was wealthy enough to have a “parlour” in which to hold a funeral. While there may not have been a parlour in every home, those of lower economic status did hold funerals within the home.

Additionally, there appears to be a lack of understanding among some participants of the ways European traditions and rituals associated with death acted as a tool of assimilation in North America. As discussed in the Introduction, Seeman (2011) argues that colonisers forced Indigenous communities to adopt European deathways and used violence when non-Christian funerary rituals were practiced. Today, genocidal practices and policies from the Government of Canada further the negation of Indigenous healing, traditions, and ceremonies associated with the end of life. Anderson and Woticky (2018) make reference to a meeting in 2016 which sought to discuss First Nations, Inuit and Metis (FNIM) strategies to palliative and end-of-life care. Emergent themes included: “differing urban and remote community experiences, the need for death education, cultural barriers, challenging interactions with western medical personal, systemic racism, opportunities for healing, and the absence of spirit in the biomedical palliative care system” (p. 53). As previously mentioned, much of Indigenous knowledge, healing and ceremony is kept as oral history and as such cultural disruption “poses a real risk of permanently losing much of this knowledge given the oral nature of Indigenous knowledge” (p. 50). In cases where traditional end-of-life care and ceremonies have been lost or for Indigenous individuals in urban locations, Anderson and Woticky suggest that “The Medicine Wheel and the Two Row Wampum offer a vision for restoring respect, balance, and spirit to the end-of-life journey” (p. 54). In Canada, where hegemonic systems support a narrow Western understanding of death and

its associated traditions, it is imperative that providers of end-of-life care understand the ways death as a ritual have been used as a tool of exclusion and violence.

As Fletcher (2019) notes, much of the contemporary literature and popular understandings of historic deathways do not account for the ways traditions around and experiences of death are influenced by race, gender, class, religion, and sexuality. During the interviews, historical understandings of death and gender intersected in interesting ways. For example, Keon notes, “You don’t walk in as a professional but more like how it used to be back in the day, when there was one woman in the community that was the midwife and she also dealt with the deaths, and the sick... I have become that person in this community where I am.” Here, Keon couples her understanding of pre-Industrial American death practices with the gendered assumption that it was women who tended to the dying prior to the medicalization of death during the twentieth century. While it is true that women tend to do the bulk of paid and unpaid emotional labour, this is still a point of view operating within gendered and Eurocentric understandings of what pre-modern end-of-life and funeral care looked like.

Moreover, the desire to replicate the pre-industrial role of a woman in a small community who tends to the sick, labouring, and dying is a frame of reference that is grounded within Eurocentric understandings of death in North America. The erasure and silencing of Indigenous deathways in North and South America is directly related to colonialism and genocide. To this, Fletcher (2019) argues that the field of death studies and by extension the death positive movement, is too rooted in Eurocentric histories and understandings of death. As such, Fletcher calls for the field of death studies to be decolonized in the following ways: give more attention to the death rituals of communities of colour; push for greater understanding of the ways systemic oppression influences the “mortality and fatality” of people of colour and marginalized

communities; decentre white, New England burial traditions; and, analyze the ways white privilege operates in the field of death studies (2019, para. 6).

Despite the core similarities between the participants and the death positive movement, particularly in their conceptualization of the history of death, there was a lack of consensus among the participants as to whether death doulas should be associated with the death positive movement. When I asked Lucy her thoughts on the death positive movement, she said: “I think it’s marvelous actually.” However, despite her support of death positivity, she also warns that:

I think with the death positive movement, I think we have to be careful in one aspect, because so many people are not ready to talk about death and if we make it all cheery it could offend or trigger. I think we just have to be careful, we have to know who our audience is. If it’s a whole bunch of university students, great! You can be death positive. Wait, we don’t know that. That’s an unfair blanket statement. I think you need to know who your audience is.

What Lucy is identifying here is the use of language in the death positive movement, as there is potential to alienate individuals using terms such as “death positivity” or “good death.”

MacDonald, Jane, and Keon had similar critiques. Keon compared the death positive movement to that icky feeling “when your creepy uncle comes and you get that feeling in your stomach but they haven’t done anything? But you feel creepy about them?” She elaborated:

There’s this whole other part of [the death positive] movement that, it’s cool to be goth-y and have expos, where everybody can draw on a casket, and pretend to shroud a body and you have a table where you have memorial stuff. And it’s all done with the sense of positivity, and the reason they’re doing it is to normalize the fact that we are all going to die. I know that because I talk about death all the time in my course but the funerals I do

are predominantly for younger people. I don't get a lot of ninety year olds because they usually belong to a church. I get calls like: "twenty seven year old dies suddenly in sleep" or "three day old baby dies from SIDS." Really tragic sad things. I have the intellectual knowledge, as everyone does, that we are all going to die at some point and we don't know when that will be. We're not all going to live to be one hundred years old. This whole death positivity thing almost feels like another form of death denial. I want to say to people don't make a mockery of this death thing, it is disrespectful.

Here, Keon describes the death positive movement as a movement comprised of many different components, which would include death doulas. However, she also identifies a sector of the movement that she finds problematic. Similar to Lucy, Keon takes issue with the use of language and activities in death positive circles due to what she perceives as a tendency to gloss over the unruly emotions associated with death and dying. Considering Keon previously identified death doulas as a "trendy" occupation, I wonder if the growing association of death doulas with the death positive movement has contributed to the sudden interest in death doula services. Though the tenets of the death positive movement arguably ally proponents with a movement to de-commodify death, if the death positive movement has made death "trendy," that could equally contribute to a landscape that commodifies death. For instance, Booth (2019) draws attention to the WeCroak app, an app that "delivers five death-relevant quotes to your phone each day." While she herself does not suggest that the app commodifies death, I would say that the proliferation of goods and services about death could speak to an environment that is looking to profit from the growing interest in and openness about death.

To MacDonald and Jane, death positive terminology such as "good death" and "death positivity" is where they find problems. MacDonald explains:



I feel the term “good death” does not fit my being and what I do because no death is good. It is sad no matter what happens. I don’t like to use the word “good death.” I like to use “dignified death.” They get to die the way they want and that was one of my big things going into death doula was seeing so many individuals who had reached out to me—aside from family and friends—it’s more so about treatments and the conversations.

Here MacDonald explains that the term “good death” does not fit her practice because, once again, the language does not acknowledge that death can be potentially sad, tragic, and traumatizing. In place of “good death,” MacDonald elaborates on her preferred terminology “dignified death” to describe a death that respects the wishes of the dying. Jane, whose point of view is similar to MacDonald’s, says:

I don’t like death positive. I like saying “death awareness”. Because it isn’t all positive and I don’t want to sugar coat it, and I don’t think any of us should sugar coat it. There’s a lot of emotions and I would hate to add to that taboo, to that death denial that it’s great and rosy if you’re making all these choices—no! There’s going to be hard moments. Life isn’t always positive. Death isn’t always positive. I initially called myself a death doula, but now I say end-of-life doula because we perpetuate that misconception because when you think of a death doula you think of it as only at the time of dying. But yeah, death awareness sits better with me. Again, for those who are out there and are being the face of that death positive movement, at least we are talking, at least we are getting the conversation moving. That’s my positive take away from it.

Notably, Jane does not personally identify with death positivity, since she believes the language “sugar coats” the negative emotions associated with death; nonetheless, she believes it is positive that “we” (society as a whole) are speaking about death more frequently.

When placing Lucy, Keon, Jane and MacDonald into conversation, we can see that they believe that the use of language is very important when it comes to death since there is no guarantee that a death will be “good” or “positive.” Their misgivings about the death positive movement stand counter to narratives that often place death doulas supporting death reform within death positive circles. Because death doulas remain a largely unregulated profession and therefore perform a wide variety of end-of-life and funerary care, they are not easily placed within the so-called death positive movement. Perhaps if they were regulated, their roles would be more defined and thus limited, which is at least part of what some death doulas themselves fear. If they were regulated, their roles would be more defined and thus limited.

### **Filling or Creating Gaps? Education and the Commodification of Death**

As previously indicated, MaryMoon believes that death doulas were created as an alternative to conventional end-of-life and funeral care. Adding to this claim, Nikolajev describes death doulas as “bridgers” of gaps between end-of-life and funeral care. In agreement with both of them, Jane stated,

I find we [society in general] support people really well in health care and we don't really talk about the parts of dying. We don't talk about funeral options, about interment... And so people go from being really supported in health care to then a funeral home where they will get information about that funeral home but not all the choices that exist within someone's province.

In other words, Jane believes that while there are supports in place while one is alive, that support does not extend to funeral care, a field that people may have to navigate while in a state

of grief. MacDonald concurs, believing that death doulas have the potential to fill the “gaps” in the medical system. She offers the following example:

The family is in all this chaos on this rollercoaster. And there’s PSW [personal support worker] teams coming in the home, nurses, doctors and community workers. They’re in chaos they have no idea what’s going on. These people are trying to help with their skillsets. They’re there to do specific jobs, they don’t have time to fill that gap where there’s an emotional need for connection. And they need to be guided, the family almost needs a liaison between the two where you’re going back to the medical team and telling people what others told you and are collaborating. I always say it takes a village to die. And that village is imperative to all of us in the industry, from doctors to funeral homes to death doulas to again work together and to respect the other person’s role.

In her experience, MacDonald finds there is a lack of cooperation between medical providers. The chaotic setting she describes features multiple rotating providers who may not necessarily communicate among themselves let alone with the client and family. In her mind, a death doula can fill the role of a navigator, and to borrow Nikolajev’s word, “bridge” the gaps of service, helping the dying and their loved ones navigate this field and better understand their options. In many ways, the emergence of the death doula can be understood as the emergence of a provider to reshape the ways in which end-of-life care and funeral care are received. However, in the ongoing project of death reform there does not appear to be consensus on how to improve access to affirming end-of-life and funeral care. Nor is there a coherent understanding amongst the public -- and even amongst death doulas themselves -- about who death doulas are and what they do. In addition, while death doulas may potentially be a good support in palliative care, there are no studies that can point to whether or not they would be a cost-effective option for governments

to implement in formal end-of-life care systems. Alternatively, while death doulas could potentially be helpful acting outside of professionalized environments, there are presently no safeguards in place to protect their clients from potential abuse.

In addition to the lack of data available, one of the main challenges in researching death doulas is the lack of consistency about who death doulas are and what they do. As stated in the introduction, death doulas have been described as offering informational and emotional support (Davie, 2019), “spiritual support for the secular” (Browne, 2015), and home funeral support (Watson, 2016). These accounts of the services provided by death doulas are all very different. What’s more, intentionally or otherwise, some death doulas seem to appreciate and/or benefit from this lack of consistency in defined services. As Lucy explains,

Every death doula is different. We all have our different beliefs and talents and different backgrounds. Some death doulas will have a medical background, some death doulas will have a pharmaceutical background, some death doulas will have an energy healing background. We are all so different, there isn’t really a standardized board that regulates a death doula.

Here Lucy frames the variance in death doulas as a positive, as there are a variety of death doulas to fit different needs. However, not all death doulas see the lack of consistency as a positive, as Jane explains,

There’s been tension in regards to what our role is and what the misconceptions are. For the funeral professionals I believe they are concerned about our training, they are concerned we might be passing on information that isn’t accurate. There may be concerns that we are trying to monetize our support, and I think they might be worrying that we are not following a scope of practice and ethics.

In Jane's estimation, due to the lack of consistency and regulation, professionals (funeral professionals in this instance) are confused about the services death doulas offer and are suspicious of their intentions. As I discuss below, to understand why there is so much variance when it comes to the roles and responsibilities between death doulas, it would be important to consider the education and training that informs their practices.

Because there is no governing body and no professional regulation of death doulas, there are no identified core competencies that can be mutually agreed upon to "certify" a death doula; that said, there is an abundance of training programs that claim to provide the student with the necessary knowledge to work as a death doula. Presently there are six training programs across Canada that provide instruction to would-be death doulas (see Appendix D). When reviewing and comparing tuition for the certification programs, one finds a wide range of fees, with the lowest being the Soul Passage Death Doula course in Alberta at \$249 CAD and the most expensive being the Sacred Passage: End of Life Doula Certificate offered by the Conscious Dying Institute, also in Alberta, at approximately \$2495 USD. That is a substantial sum of money (and difference) to spend on a course for an unregulated profession.

In fact, death doula education and training emerged as one of the most important subjects from the interviews. Moreover, as we shall see, the proliferation of programs potentially speaks to the commodification of death. While participants regarded education and training as a potential benefit, they also identified it as a potential source of conflict and concern. The death educators in the group reflected on their role as teachers and, more particularly, whether their students would heed or disregard their lessons. Furthermore, they raised concerns about the monetization of training programs and their ability to provide adequate instruction. On this subject, Keon says, "Do you know who I think is making the money in the whole death doula

movement? Are the people who come up with trainings. I think that's who's making money.” Here Keon suggests that training programs are profiting off an unsustainable profession.

During the interviews, the participants stressed that not only is formal education important for becoming a death doula, but that it is crucial to determine the right form of training. MacDonald states:

Because the whole industry is fairly new, there are a lot of training programs out there. Individuals really need to do their research and make sure they are attaching themselves to a reputable form of training. That can be a challenge out there right now due to the regulation. I have been approached many times, ‘well can you create a death doula training course?’ And sure I can! But that’s not my skillset right now.

MacDonald indicates that it can be difficult to determine whether or not a training is reputable due to the proliferation of courses and the lack of regulation. Of interest here is MacDonald’s statement is that she has been approached to create a training program, but turned the opportunity down since that is not her current focus. As for the other participants, while they all agreed that formal training is important, they were not in agreement on who offers a reputable training course. Moreover, while they trust their own training, they are skeptical of the training from other programs they did not attend. In relation to the broader project of death reform, it appears that there is not a path agreed upon by the participants in the death doula movement.

Nikolajev works as an instructor for the death doula training program at Douglas College, the only training program for death doulas offered by a college. The course claims to provide students with the ability to

Describe end-of-life care and the role of the end-of-life doula; discuss a range of beliefs and practices surrounding death; demonstrate effective communication skills; understand

the complexity of grief and demonstrate effective responses to expressions of grief; understand and demonstrate the use of Advance Care Planning tools; understand the legalities of funeral practices in the Province; and understand the end-of-life doula community of practice (Douglas College, n.d., para. 3).

In other words, the Douglas College End-of-Life Doula Training Program seeks to provide their students with practical knowledge to understand provincial legalities with respect to funeral practices and advance care planning. In comparison to other programs offered, the Douglas College course costs \$750 to attend, and is in the middle range when evaluating tuition costs. The program requires a short time to complete with five days of in-person sessions. In comparison, the BEyond Yonder course takes twelve weeks to complete and the Conscious Dying Institute course consists of four to five live Zoom sessions and six days in person (Appendix B).

Nikolajev disclosed her fear that students would not heed the lessons of their education. As an educator, Nikolajev says she teaches from “the perspective that no one is going to check on you,” and therefore has the fear of students “going rogue.” When reflecting on the training programs for death doulas, Nikolajev provided a commentary on her perspectives of programs currently offered in Canada. She said:

Douglas College is a gear [sic] towards more so the professional side... If you go onto their site, they are following the lead of the End of Life Doula Association of Canada so, that is in the professionalization. But there is a whole other group of folks, Conscious Dying, Institute for Traditional Medicine in Toronto and there are other folks... Home Hospice Association is a new association in Ontario providing Death Doula workshops, but again I have no idea what they teach. I have been told that what I am providing

through Douglas College is like guts and meat because of the practical angle. I have had some reflection that the one from the Institute of Traditional Medicine is not open to some of the realities of the funeral industry and the changes within.

She also argues that:

From that perspective of Douglas College, as a facilitator and ensuring that the death doulas get the information they need for this new profession... My understanding: if it's coming from a college it has some form of credential. Especially when you have a college that has been in the business, they launched the first birth doula program, they have a reputation there. So, there's already a built trust in that perspective.

These statements demonstrate that Nikolajev feels training is more credible when connected to an accredited institution such as Douglas College. She implies that history is important when it comes to choosing a training program, and since Douglas College launched the first training program for birth doulas, their reputation and trust should carry into their end-of-life doula program.

The Douglas College program potentially fits into the project of death reform. If the programs are as practical as Nikolajev suggests, then it would appear that Douglas College is attempting to provide training for and legitimacy to an emerging profession. However, considering death doulas have an undefined scope or practice, undefined entry level competencies, and a lack of oversight post 'certification', it is presently unclear if Douglas College is contributing to the lack of consistency in death doula practices or if they are trying to establish professional parameters for aspiring death doulas. However, considering Douglas College was the first accredited institution to establish the first birth doula course, this perhaps speaks to a history and pattern of capitalizing on potentially unorganized, emerging professions.



Ultimately, the path of death reform and the path of commodification -- and their intersections -- are complex subjects, and multiple truths can exist at once. All of this is to say that death reform and commodification are not necessarily polar ends on a binary track, i.e., commodification can occur through professionalization as well as in environments lacking consistency and regulation.

Not every participant made known where they studied. Lucy, however, did. She studied at the Institute for Traditional Medicine (ITM). While she did not provide a concrete statement about her time at ITM, she generally spoke in a positive tone about her education. According to Nikolajev, as you may recall, ITM “is not open to some of the realities of the funeral industry and the changes within.” Nikolajev did not elaborate on what she means by this; however when speaking about the death positive movement, she claims that some individuals view the funeral industry as an overly negative institution since they “stitch and glue you.” However, she wants to remind those involved in the natural burial movement that, as she says,

Death is still going to cost you, let’s not be naïve in the thinking that everyone can have a natural burial and it’s not going to cost you anything. There are fees and fines for the safety of society to make sure we bury the dead with dignity.

Here, Nikolajev appears to take a practical stance against what she fears is an overly idealistic view of plans from natural death proponents to reform the funeral industry. While not directed towards ITM but at those who are involved with natural death broadly, Nikolajev’s statement about death still costing may give some insight as to what she meant by some institutions not “being open to the realities of the funeral industry.”

As discussed in the previous chapter, after being asked to become an instructor at a death doula-training program, Keon was appalled by what she witnessed in the program she sat in on. Keon claims that there presently is not a demand for death doulas; and, she identifies those who

run the training programs as the ones making money in this business. While death doulas arguably exist because of a push against the commodification of death, Keon's comments about her experience being recruited by a training program illustrate that death educators may be profiting off the growing interest in death doula work:

You have people doing trainings that are essentially regurgitated information you can pull off the internet! That's not training anybody, that's not sharing knowledge you gained from experience, that's just regurgitating information. TEDTalks and that kind of thing, that's not teaching. When you're doing that and you're charging hundreds of dollars .....yeah, someone's making money. The people who are doing the training are making a lot of money! And the people that are taking the trainings are not getting the value for what they are paying, and they are under the impression that now I can just hang out my shingle, do up a business card and I'm a death doula! And then they find out very quickly there isn't a demand for it. Even though in the media we are seeing every week, CBC practically every week is doing stories about death doulas but it's not in high demand.

Keon's misgivings about the death doula profession are complicated and, as I have mentioned, run through many threads, including, monetization and cultural appropriation. Essentially, she is implying that training programs are teaching information that is accessible online and there is nothing specialized (that warrants an exorbitant price tag) about the education death doulas are receiving. Since there is what I identify as a lack of entry-level competencies, there is no guarantee that a death doula educator will have enough experience to teach effectively. Further, since there is no standardized curriculum for death doula education there is the potential for great variance between training programs and educators.

Continuing the discussion of training programs, Keon argues that cultural appropriation is present in training programs. She says,

I'm still not sure how to articulate it without offending the people who are doing good work. It's like when you have a thirty-year-old white woman, privileged, who shows up and says "I'm a shaman." Or like in the death doula training um... for lack of a better word the trainer says "you're probably going to be asked to do funerals!" And I'm like, "Are you kidding me?" I spent eight months of intensive study about ceremony creation. That's an insult to my profession as a celebrant that you say to someone all willy nilly light a candle and burn some sage and now you can do these rituals. Which isn't what rituals are about. That's my concern. People who are not qualified showing up and offering these services. If you want to show up and hold someone's hand and be comforting that's one thing, but if you're showing up and dancing around and pounding a drum and you're white. I have to keep going back to that... Because celebrants in our training it is pounded into our brains to be respectful and careful of cultural appropriation. When I do a welcoming ceremony, I don't pour water on a baby's head because I'm not a minister or a priest. It's not my right to do religious rituals because I'm not clergy. So, when you have death doulas who do a weekend workshop and are then all of a sudden are a shaman? That's what I have a hard time using the term death doula, because I don't want to be identified with that.

To remind readers, Keon describes herself as a heterosexual white woman. Throughout the interview, she expressed discomfort with white death doulas appropriating from Indigenous cultures. Keon's comments here link commodification, unprofessional conduct, and cultural appropriation, suggesting that aspiring death doulas are being taught or encouraged to provide

religious ceremonies that she believes they are unqualified to provide. It is worth revisiting Keon's role as a Life-Cycle Celebrant in this moment to remind readers that Keon primarily works with secular clients looking for personalized ceremonies for their important life moments. In the above statements, she indicates a discomfort with appropriating religious rituals she is not qualified to provide. When I asked for an example of what her clients ask her to facilitate, Keon said,

A little example of making ritual meaningful would be when I met with a family and they talked a lot about how their father, who died. He spent a lot of time in his garage with his wood stove and he would sit out there in the evening. That's where he'd do his self reflection, listen to the radio and whatever. So, rather than using the silica clay that funeral directors use at a burial when they do the "ashes to ashes dust to dust" piece, I asked the family to bring a jar of ashes from his woodstove. That's what we sprinkled into the grave. It's hearing about who the person was and being able to really grasp onto the things that stand out for everybody. Then you create rituals and talk about music that would be suitable and where that music would best suit in the ceremony, and how you can get all the people there involved in the ceremony so they're not just sitting there listening to something that could be applied to anybody.

From this statement, Keon appears to be offended by death doulas who provide what she views as shallow rituals appropriated from cultures they are not a part of. Keon's criticisms of death doula training programs appear to be two-fold: 1) aspiring death doulas can be financially exploited by unqualified educators, and 2) newly trained, potentially unqualified, predominantly white death doulas are providing services that are caricatures of non-Western traditions and ceremonies. Both of these criticisms are linked to commodification, as students who are

enrolling in death doula training to either become doulas themselves or supplement their own knowledge are potentially not receiving a fair value exchange. This speaks to an educational environment where content and delivery may come second to profit. Keon's second point is reminiscent of what Lau (2015) terms as "New Age capitalism." As Westerners go to yoga, drink turmeric lattes, attend Reiki therapy, and eat superfoods from non-Western cultures, "a way of life becomes another commodity to consume and to sell" (Lau, 2015, p. 6). Lau argues that the promise of better health and wellness is reliant on the services and goods to obtain it, as such alternative medicine is "commodified, sanitized, and thus neutralized for easy consumption" (2015, p. 12).

In addition to her concerns about cultural appropriation, Keon continues by arguing that, in her experience, some training programs are not:

Aware of things like the law with handling bodies and things like that. That's where it's concerning. It's a free for all, willy-nilly, people might take a course through the United States and not think to check the laws for their own province. Things like that, that's what's concerning to me. I don't know how you resolve that. Death doula trainings are a dime a dozen.

Here, Keon appears to express concern about the proliferation of training programs, in both Canada and the United States. The "free for all" she describes speaks to the suggestion that educators are not focused on specific and relevant education. It is worth considering her comments in relation to Nikolajev, who also claims authority in terms of training as an educator at Douglas College, a program she claims provides practical knowledge to death doulas. Outside of her fear that a student may "go rogue," a statement that may speak to the lack of oversight for death doulas as well as the quality of their education, Nikolajev did not provide many critiques

of the death doula-training industry. She states that “I teach from the perspective that no one is going to check on you” and “the first thing I teach death doulas is: who are you? How are you going to serve? I think there are folks within the system who have the opportunity to transform it. They are positioned well.” In these statements, Nikolajev speaks optimistically about the potential of her students to “transform” the systems of end-of-life care from within, and while that may be true of students who receive well-informed education, not every program offers such education. It appears that the lack of regulation of death doulas has enabled the commodification of education specifically, where educators, well intentioned or not, are in a position to financially exploit the growing interest in this emerging profession.

Though Keon is distancing herself from the death doula title, she advises aspiring death doulas to follow another route:

Go to a hospice and do the volunteer training. It’s thirty hours and then go and get some experience sitting with people who are dying. Learn from the palliative nurses. That’s what we used to do as birth doulas, learned from the labour delivery nurses because they’ve been doing this for twenty years. You learn from the midwives. Go and do that for a while and see if it’s something you actually want to do.

Here Keon advises would-be death doulas to avoid the training programs as a first port of call. Instead, she suggests that they volunteer first and encourages interested parties to take hospice volunteer training before they commit to formal death doula training. Her comments stand counter to the calls from Nikolajev, Jane, and MacDonald to take formal death doula training, but do align with MaryMoon’s concern about training programs potentially commodifying a movement that was supposed to be “more economical” and “more hands on.”

After interviewing the participants, I conclude that the subject of training is a significant area for concern with regard to the death doula profession. There is not only disagreement about what is valuable in training curricula, but also concern about educators' apparent intention for profit over content in delivery of death doula programs. There are approximately six death doula training programs across Canada, and as Keon points out, those programs do not include American courses. Moreover, the fact that there is no standardization of current curricula places the death doula at some risk, especially if some programs do not instruct students about the legal parameters of the role. The determination of cost for the program is wide and varied and reflects that lack of consistency or value in the course content. These problems have negative effects on both the would-be death doula and their potential clients. Is there a way to fix these problems? The participants are not sure. While MacDonald believes professionalizing and standardizing the death doula is a step towards establishing credibility, MaryMoon, Nikolajev and Jane disagree. In the following section, I present participant opinions on whether or not the death doula should be professionalized, a subject that directly relates to questions of death reform and commodification.

### **Professionalization of the Death Doula**

According to *Lexico Dictionaries*, professionalization refers to “the action or process of giving an occupation, activity, or group professional qualities, typically by increasing training or raising required qualifications” (n.d.). Though the majority of participants believe that professionalization and regulation is not necessary for death doulas, two participants disagreed. For example, when I asked Jane about her opinion on regulation, she provided an answer that did not necessarily take a side in this debate. She said:

I didn't think so in the beginning, and I'm a tough one because I see all sides of everything. I really believe every family could and should, if they wanted to, support their own in dying. A big concern came about a year and a half ago when I got a phone call from someone who wanted to become a doula. As I was discussing legalities she said she was just going to Google things and become a doula from research online. When I mentioned some of the legalities about dying, about how we don't touch a body after a person has died for pay because otherwise we could be fined, she responded: 'Well I still have to be paid.' And I said: 'Well I'm just letting you know some legalities so you don't get in trouble.' I was left with a sense of 'Oh my.'"

Here, Jane articulates what she frames as an alarming experience with a potential death doula who did not appear to be willing to take the proper steps to educate herself. Or, perhaps, the concern is that this person would potentially, knowingly disregard the law since she needs to be paid, another issue that points to the commodification of death doula services. When I asked if these types of exchanges were becoming more common, Jane said:

Thankfully no, but I had that one call, which was enough to raise concern. For the most part even as an instructor, that people come to class actually for their own learning and for their own relationship with dying. With their death. And they leave not necessarily wanting to become a doula, but they leave with a more sense of fully living their own life... And the trendy thing, I've seen some of it. I call it the 'ick factor.' There's a lot of courses out there. Here's my truth, at least people are talking more. So, that's my take away. If it's opening up doors so that people can talk a little more about it then that is part of the movement. And there's going to be a spectrum of different approaches and I have to trust that I can only show up ethically in the way I show up.



Jane appears to answer this question with good faith, meaning that she is hopeful that the sudden interest in death doulas is opening conversations about having a sustainable and healthy relationship with death. In this way, she links death doula training to contributing to a richer understanding of and engagement with death, and thus, to the death reform movement. However, while Jane trusts that she herself can show up ethically and professionally, her comments -- and those of other participants -- suggest that there is no guarantee that other death doulas will follow suit.

By extension, not all death doulas may see themselves as part of the death reform movement or believe they contribute to it. Rather, they may engage in practices that are antithetical to death reform. In this case, Jane's conversation with the aspiring death doula is an example of an individual who may be acting counter to death reform. I wonder if Jane's lack of confidence in the system is due in part to the fact that the person she spoke to (and others) stand to become death doulas in this quick manner and may not possess the necessary skills to be successful in this role. This exchange may raise the question for Jane as to why she, or anyone else for that matter, should go through all this education for the same professional outcome. To my mind, it also demonstrates the importance of having a standardized education for death doulas.

Of all the participants, MacDonald, who is a business owner and death doula provider, was the most vocal in her opinion that death doulas should be regulated. MacDonald believes regulation will lend credibility to death doulas and will result in respect from medical professionals. As she explains,

You're going to hear that some death doulas do not want regulations because it will tie their arms in doing what it is they want to do. In my opinion, my experience is, yes I want

it to be regulated. For a few reasons. First and foremost: credibility. Once we are regulated the medical professionals will understand what it is we do, know that we are regulated, and that we are not crossing over into what they do. They will know that we are being monitored and that is very important to build relationships. One of my mentors is one of the head palliative care educators in my region and we talk about this all the time. Her big fear—she would love to have death doulas in hospice, in hospitals—but her big fear is that she has met many death doulas who don't necessarily stay in their own lane. They will say: 'Oh, they have you on that medication? Oh, that's a little bit too strong.' How do you know that? You're not a doctor! So, stay in your own lane as a death doula and that will help all of us progress in the future, so the ones that don't [stay in their own lane] create that bad taste for professionals that have been to school for years and years and years. We have to respect what it is they do in order to work together with them. The other reason I'd like it to be regulated as well is not only for credibility but also for consistency. I feel like it is important for the integrity of death doulas is to be consistent and being regulated would help that very much. So just like birthing doulas. My sister-in-law is a birthing doula and she has been for years and years. It is finally regulated. Things changed in the industry, some say for the worse others for the better, but at the end of the day there's a board that they can turn to and there is a mentoring body that is monitoring and mentoring you.

MacDonald wants death doulas to be regulated so that they are seen as credible and are accepted by the medical field, and she also wants death doulas to be consistent in their service offerings. MacDonald's statement suggests that medical professionals are wary of death doula services, a claim echoed by Jane who stated that funeral professionals do not trust death doula training and

are afraid they are passing along incorrect information to their students in addition to trying to monetize death doula support.

Lucy makes some similar points. Although she expresses misgivings about professionalization, she also states, “on the other hand, it might legitimize it more. Knowing there’s a governing body. Because I think that is an obstacle. Does it feel legitimate because it’s so new?” However, while Lucy sees the logic in professionalizing death doulas, she ultimately believes that professionalization will “do more harm than good.” Lucy’s reasoning harkens back to her suggestion that professionalization will make death doula services less “caring and nurturing” as discussed in Chapter 3. Lucy connects death doula services to gendered care-work, suggesting that regulation will hinder and limit the caring work she provides.

While Keon distances herself from the death doula profession, she does not believe in its regulation. She explains:

I don’t like the idea of regulation because I saw what happened to [birth] midwives when they became regulated, it was awful. I think there needs to be more guidelines as far as an acceptable code of ethics or scope of practice, whether it’s done provincially or whatever. The thing is death doulas are not responsible for anything medical, it’s not like something bad will happen if the death doula holds somebody’s hand. But with birth you’re dealing with a human being born and there’s potential for disaster or birth doulas not behaving appropriately. With death it’s a little different because you can’t screw it up. The person is dying and then they die you’re not going to screw it up.

Here Keon suggests that regulation for death doulas is unnecessary since, in her words, you cannot “screw up” something as inevitable as death. However, this statement frames death as having a straightforward trajectory, which is a myth. Further, she believes that death doulas only

need guidelines for a scope of practice to follow. This may be a preferred approach due to the low numbers of death doulas; however, more oversight may help to build accountability and provide structure to work within. While Keon did not elaborate on why she believes the regulation of birth midwives was “awful,” it appears that the crux of her argument about death doulas rests on the death doula’s inability to do harm to their clients, because they will die anyway. I found Keon’s stance against regulation surprising considering her concern about training programs that provide potentially harmful information and that are not mindful of provincial legislations. Because death doulas are workers who interact with vulnerable individuals, including the dying client and/or their friends and family, I would argue that there is a risk of abuse especially if the death doula is either uninformed or ill intentioned. Further, there is potentially a risk for death doulas themselves: if they were to give incorrect advice, if something were to go wrong or if someone were to experience trauma during the dying process, they could face blame and other negative consequences.

Joining Keon in her stance against regulation, but for different reasons, MaryMoon believes it is not feasible for death doulas to survive while being regulated. In her words,

Some people who want to go through the whole certification, like third party certification. You can get a certification of completion from anybody you study with but it has no power or effect beyond that community of people. So we are talking about third party certification, such as nurses, doctors, osteopaths, or accountants or lawyers or whatever. There are some people who are looking in that direction, specifically because they want death doulas to be working in hospices and be considered trained staff. But for the most part we don’t want to be certified. We don’t want to go through the massive work that requires staff to run an organization, and insurance, and... dues.... Midwives in

BC pay the highest membership dues per year and it's over \$2000. So, not wanting to get into that because right now, realistically, very few of us are earning a living doing this.

Most of our time is spent educating.

From this excerpt, we can assume that MaryMoon does not want to be integrated into mainstream health care systems because, as she sees it, belonging to an institution with formal oversight would be too much work on an organizational level, especially when very few death doulas earn enough to make a living. In effect, she claims that if she had to spend money on insurance and membership dues she would not be able to make a living. Furthermore, we can connect MaryMoon's statement to the suggestion that death doulas and death midwives were created to make death more hands on and economical. In other words, MaryMoon apparently believes that death reform can only occur outside of the hegemonic systems that currently manage end-of-life and funeral care, since the present system does not encourage familial care of the dead and dying. However, it is important to clarify that the BC Midwives dues are not necessarily over \$2000. Their malpractice insurance is \$1800 annually and their dues to the professional association are 2.9% of their income (2016, p. 11). Nonetheless, it is true that the majority of death doulas are not earning living wages for their work.

However, considering their own expressed concerns about inconsistencies in the death doula-training industry, aspiring death doulas and those who take the course for their own knowledge are unprotected and left out of this picture. Because they are potentially unaware of the inconsistencies in the training industry, they may be at risk of being taken advantage of and further, may also inadvertently pass along incorrect knowledge themselves. While death doulas are working with vulnerable individuals, is there a point to regulating them if they are so few in number and are not in high demand?

## **Conclusion**

Popular media and scholarly writing have framed the field of Death Studies, and the death positive movement, in particular, as a monolithic field where the proponents are in agreement about their goals and core tenets. However, as participant interviews indicated, this is not always the case. The participants relayed their critiques about the death positive movement and the language that frames calls for reform of end-of-life and funeral care, thus indicating that there may be more heterogeneity in the field of Death Studies and death care-work than the literature presents. Further, while the majority of participants were in agreement about not wanting professional regulation, their reasonings were undefined and speak to a lack of guarantees about group accountability. The tensions between commodification and professionalization suggest that while some participants, mainly MacDonald, may see professionalization as a strategy to gain credibility and consistency for death doula practice, others see professionalization as potentially hindering and limiting their scope of practice. Lastly, the participants' comments about education and training speaks to a possibility of educators and institutions commodifying the interest in a profession that lacks a cohesive scope of practice, curriculum, and professional standard. The upshot is that it is hard to provide a definitive description of what death doula do and/or what their role is in the death positive movement.

## **CONCLUSION: OVERALL FINDINGS AND DIRECTIONS FOR FUTURE RESEARCH**

This thesis offers a phenomenological exploration of the landscape of death and dying in Canada with a specific focus on the emerging role of the death doula in Canadian end-of-life care. I sought to answer three specific questions: How do death doulas fit into a larger project of death reform? In what ways do death doulas resist or reinforce the commodification of care-work? How might hegemonic beliefs about death, gender, and social privilege complicate any roles they might have in the death reform movement? This study is exploratory and due to the small scale of the research, I do not extrapolate the findings to the wider death doula community. However, this research does provide a view into the world of death doulas in Canada and may point to a series of possible directions for research on a larger scale.

I investigated the death doula as a source of non-medical support by using feminist phenomenology. This enabled me to study in detail the participants' perceptions of their work as death doulas. While I do not identify any problems with my methodology, in hindsight, I recognize that my research design was flawed with regard to participant recruitment. I believe recruitment would have been smoother had I used a snowball approach.

With regard to my first question, How do death doulas fit into a larger project of death reform?, I argue that the participants both contribute to and resist death reform. They also describe interactions with other death doulas that can be described as antithetical to death reform. While popular media outlets often associate death doulas with the death positive movement, many of my participants disagreed, indicating that death doulas may not be as supportive of death positivity as present literature suggests. Instead, they appear to variously align themselves with multiple overlapping movements including the alternative death movement, the death doula movement, and the community death care movement. Participant comments suggest that there is

more nuance to these movements than present literature indicates, which could be a potential avenue for further research.

Since popular media outlets often include death doulas as being involved with the death positive movement, a major focus of this study is dedicated to nuancing that stance. For the participants, many vocalized disagreement with the death positive movement, often objecting to what they claimed to be alienating language that does not leave room for grief or negative emotions in response to death. Rather than the death positive movement as a sole, homogeneous movement, I identified a number of movements dedicated to reforming societal relationships with death including, the community death care movement, the death doula movement, and the alternative death movement. Since many of the participants did not see themselves as participants in the death positive movement, but spoke of being involved in death doula movements or community death care movements, this suggests the existence of movements that operate separately from, or in an overlapping manner with, the death positive movement. For instance, several participants seemed to speak of death doula work as a movement in itself. At the same time, since how one views the movement and death positivity is highly variable, one person may see their involvement in the death doula movement as death positive while another may not. Further, some participants suggested that applying a cheery positive stance to death, while well intentioned, could in itself be a form of death denial. Additionally, the surge of interest in death positivity could contribute to the commodification of death reform movements as seen with the proliferation of workshops, courses, and death-centric merchandise.

To answer the second question -- In what ways do death doulas resist or reinforce the commodification of care-work? -- Training emerged as a major focal point for the participants. Their comments suggest that there is disagreement about what they see as valuable in a training



program. Additionally, the participants voiced concerns about educators' apparent unethical intentions for profit over value in death doula programs. Certainly, death doula education would appear to be an important avenue for future research.

Professionalization also emerged as an important subject with regard to commodification, as a vehicle that can potentially reinforce or deter commodification. Only one participant indicated that she desired professional regulation of death doulas, believing that regulation would make death doula practice more consistent and reputable, while those who were against regulation largely believed regulation to be limiting. However, these perspectives together with the proliferation of training programs and the legal challenges directed at one participant, suggest that a more expansive investigation of the question of professionalization seems warranted.

In relation to the third question -- How might hegemonic beliefs about death, gender, and social privilege complicate any roles they might have in the death reform movement? -- the participants generally conceptualize their work within hegemonic understandings of gender, where caring labour is described as inherently altruistic, while at the same time acknowledging that they should not have to offer unwaged work. Additionally, one participant suggested that the death doula community has an uncomfortable connection to cultural appropriation of non-Western spiritual practices. While the scope of this study is too limited to apply these findings to the broader death doula community, the subject of cultural appropriation in death doula communities would appear to be an important potential subject for further research.

While I was not able to explore many subjects due to the limitations and scope of a Masters thesis, I have identified several potential avenues for further study, including the subjects of cultural appropriation and a deeper look into the training programs. In conclusion, this research confirmed that death doulas are indeed a potential source for non-medical support

for those seeking to arrange their affairs prior to the end of life. At the same time, participants identified concerns within the death doula movement, such as training, scope of practice, and lack of oversight. The question of professionalization proved to be important. While many of the participants identified concerns about death doula services and work, the vast majority of participants did not believe in regulation because it would limit their scope of practice. Further, many participants pointed to the connections between conceptions of gendered care-work and monetization: that is, they simultaneously spoke of providing altruistic volunteer work, but also believed they should not be “martyrs” to unwaged work. Overall, the findings from this thesis suggest that there is value in pursuing further research into the changing landscape of end-of-life care in Canada. In this thesis, I not only offer insights into the ways in which hegemonic practices in healthcare and funeral care are not serving the needs of everyone, but also add nuance to the ways movements for alternative death practices are conceptualized and understood.

## APPENDIX A

**A site visitor just submitted a new Contact Form**

**<https://www.homehospiceassociation.com/>**

**Message Details:**

**Name:** Alana Tumber

**Email:** artumber@mun.ca

**Subject:** Death Doula Research Inquiry

**Date:** March 13, 2019

**Message:** Hello, My name is Alana and I am a student currently obtaining my Master in Gender Studies at Memorial University. My thesis is about the role of death doulas and how they are currently shifting the landscape of death and funeral care. I will be returning to Toronto to hopefully conduct interviews with practicing death doulas and was wondering if you would be able to assist me. Do you know of anyone who may be interested in participating? Or do you know of any Toronto based death doula organizations I should contact? Thank you for your help.

Alana

**Home Hospice Association**

**RE: New message via your website, from artumber@mun.ca**

**Date:** March 13, 2019

We would be happy to participate –I have copied Merri-Lee Agar on this email as she is the creator of our Death Doula Training as well as a lead developer on our Hospice at Home

Program. She will be able to work with you directly to gather as many interviewees as you require

Thank you so much for this opportunity and we look forward to working with you

TR

## APPENDIX B



Interdisciplinary Committee on  
Ethics in Human Research (ICEHR)

St. John's, NL, Canada A1C 5S7  
Tel: 709 864-2561 icehr@mun.ca  
[www.mun.ca/research/ethics/humans/icehr](http://www.mun.ca/research/ethics/humans/icehr)

|                      |  |
|----------------------|--|
| ICEHR Number:        | 20200987-AR  |
| Approval Period:     | December 9, 2019 – December 31, 2020   |
| Funding Source:      | Not Funded   |
| Responsible Faculty: | Dr. C. L. D'Arcangelis & Dr. S. Boon<br>Department of Gender Studies             |
| Title of Project:    | <i>Death Becomes Them: Death Doulas, Gender, and the Commodification of Care</i> |

December 9, 2019

Alana Tumber  
Department of Gender Studies  
Faculty of Humanities and Social Sciences  
Memorial University of Newfoundland

Dear Alana Tumber:

Thank you for your correspondence of November 19, 2019 addressing the issues raised by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) concerning the above-named research project. ICEHR has re-examined the proposal with the clarification and revisions submitted, and is satisfied that the concerns raised by the Committee have been adequately addressed. In accordance with the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2)*, the project has been granted *full ethics clearance* to December 31, 2020. ICEHR approval applies to the ethical acceptability of the research, as per Article 6.3 of the *TCPS2*. Researchers are responsible for adherence to any other relevant University policies and/or funded or non-funded agreements that may be associated with the project.

The *TCPS2* **requires** that you submit an Annual Update to ICEHR before December 31, 2020. If you plan to continue the project, you need to request renewal of your ethics clearance and include a brief summary on the progress of your research. When the project no longer involves contact with human participants, is completed and/or terminated, you are required to provide an annual update with a brief final summary and your file will be closed. If you need to make changes during the project which may raise ethical concerns, you must submit an Amendment Request with a description of these changes for the Committee's consideration prior to implementation. If funding is obtained subsequent to approval, you must submit a Funding and/or Partner Change Request to ICEHR before this clearance can be linked to your award.

All post-approval event forms noted above can be submitted from your Researcher Portal account by clicking the *Applications: Post-Review* link on your Portal homepage. We wish you success with your research.

Yours sincerely,

Kelly Blidook, Ph.D.  
Vice-Chair, Interdisciplinary Committee on  
Ethics in Human Research

KB/bc

cc: Supervisors – Dr. C. L. D'Arcangelis & Dr. S. Boon, Department of Gender Studies

## APPENDIX C

### Informed Consent Form

Title: Death Becomes Them: Death Doulas, Gender and Advance Care Planning

Researcher(s): Alana Tumber, Department of Gender Studies,  
artumber@mun.ca

Supervisor(s): Carol-Lynne D’Arcangelis, Department of Gender Studies |  
carollynneda@mun.ca  
Sonja Boon, Department of Gender Studies | sboon@mun.ca

You are invited to take part in a research project entitled “Death Becomes Them: Death Doulas, Gender and Advance Care Planning.

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Alana Tumber, if you have any questions about the study or would like more information before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

This is a research project being conducted by Alana Tumber, a graduate student at Memorial University of Newfoundland. This study is being funded by the Aging Research Centre of Newfoundland and Labrador. As part of my Master’s Thesis I am conducting research under the supervision of Dr Carol-Lynne D’Arcangelis and Dr Sonja Boon.

#### **Purpose of Study:**

This study is an investigation into the emerging role of death doulas in Canadian end-of-life and funeral care in Ontario, Canada. I will investigate the following questions: do death doulas fit into the larger project of death reform? How do death doulas position themselves in relation to activism? What are the perceived barriers in accessing death doula services? Do death doulas resist or reinforce the commodification of care-work?

#### **What You Will Do in this Study:**

For this study, you will be asked to participate in an interview with me where I will ask you about your role as a death doula, what you perceive as challenges in your line of work, and how you see yourself fitting into end-of-life care in Canada.

#### **Length of Time:**

The interview will take between thirty minutes to an hour to complete.

**Withdrawal from the Study:**

- If you wish to withdraw from the study during the data collection period you may send me an email and I will delete the recording and the transcript of the interview.
- Participants may end the interview by verbally indicating that they do not wish to continue, any data collected will be destroyed
- Once the interviews are complete the principal researcher will contact participants regarding the findings. After your interview and before the data is integrated into the thesis, you will be able to review the transcript of your interview, and to add, change, or delete information from the transcripts as you see fit.
- If you wish to withdraw from the study following the data collection period you may do so up to one month after the date of your interview. You may send me an email to indicate that you wish to withdraw from the study.

**Possible Benefits:**

You will receive no direct benefits from participating in the study. However, your answers will contribute to a body of growing literature on end-of-life and funeral care in Canada. There is also the possibility that this study will bring greater attention and knowledge about the work of death doulas.

**Possible Risks:**

The possible risks or discomforts of the study are minimal. However, since this study concerns death there is the possibility that some questions may cause emotional discomfort. I have provided resources for counselling services in Ontario if you feel the need to seek support following the interview.

Centre for Suicide Prevention: 1-833-456-4566

Crisis Services Canada: 1-833-456-4566, or text 45645

First Nations and Inuit Hope for Wellness Help Line: 1-855-242-3310

Ontario Society of Psychotherapists: 416-923-4050

Ontario Mental Health Helpline: 1-866-531-2600

Canadian Mental Health Association - Ontario Division: 416-977-558

**Confidentiality:**

All identifying characteristics will be excluded from data collection. Participants will be assigned pseudonyms for inclusion in the thesis. Audio-recordings will be accessible only to the principal researcher, and the all identifying characteristics will be redacted from the transcription. The audio-recordings will be transcribed by the principal researcher.

The only limitation to confidentiality in this thesis is that the death doula community is small. While it is unlikely that participants may know one another, the risk is there considering they work in the same field and may be involved in the same organizations. This would therefore be a limited risk since identifying characteristics of the participant will be redacted from the publication.

**Anonymity:**

The data from this research project will be published and presented at conferences; however, your identity will be kept confidential. Although I will report direct quotations from the interview, you will be given a pseudonym, and all identifying information such as your location

or whether or not you work for or your affiliation with an organization will be removed from our report.

Every reasonable effort will be made to ensure your anonymity. You will not be identified in publications without your explicit permission. If you do wish to waive your right to anonymity, identifying features such as your name will be used in the publication.

### **Recording of Data:**

The audio from the interview will be recorded with an audio processing software on my computer.

### **Use, Access, Ownership, and Storage of Data:**

- Recordings and transcripts of the interviews will be stored electronically on a password-protected computer accessed only by the principal researcher.
- The principal researcher will be the only person who has access to the data.
- The data will not be archived
- Data will be kept for a minimum of five years, as required by Memorial University's policy on Integrity in Scholarly Research. After this date the data collected from the participants will be destroyed.

### **Reporting of Results:**

Upon completion, my thesis will be available at Memorial University's Queen Elizabeth II library, and can be accessed online at: <http://collections.mun.ca/cdm/search/collection/theses>.

Data from the interview will be presented in direct quotations or summarized paragraphs in the thesis. Identifying characteristics about the participants will be redacted for publication.

### **Sharing of Results with Participants:**

Once the interviews are complete the principal researcher will contact participants regarding the findings. After your interview and before the data is integrated into the thesis, you will be able to review the transcript of your interview, and to add, change, or delete information from the transcripts as you see fit.

### **Questions:**

You are welcome to ask questions before, during, or after your participation in this research. If you would like more information about this study, please contact: Alana Tumber at [artumber@mun.ca](mailto:artumber@mun.ca) or at 1-705-529-4767. Or, Sonja Boon at [sboon@mun.ca](mailto:sboon@mun.ca) or Carol Lynne D'Arcangelis at [carollyneda@mun.ca](mailto:carollyneda@mun.ca).

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as the way you have been treated or your rights as a participant, you may contact the Chairperson of the ICEHR at [icehr@mun.ca](mailto:icehr@mun.ca) or by telephone at 709-864-2861.

Participants reserve the right to skip any questions they wish, including in the demographics portion.

### **Consent:**

Your signature on this form means that:

- You have read the information about the research.



- You have been able to ask questions about this study.
- You are satisfied with the answers to all your questions.
- You understand what the study is about and what you will be doing.
- You understand that you are free to withdraw participation in the study without having to give a reason, and that doing so will not affect you now or in the future.

**Regarding withdrawal during data collection:**

- You understand that if you choose to end participation during data collection, any data collected from you up to that point will be destroyed.
- Participants may end the interview by verbally indicating that they do not wish to continue, any data collected will be destroyed.

**Regarding withdrawal after data collection:**

- You understand that if you choose to withdraw after data collection has ended, your data can be removed from the study up to one month from the interview date.
- After your interview and before the data are integrated into the thesis, you will be able to review the transcript of your interview. You must contact me within one month after receiving the transcript if you wish to make changes or to withdraw.

I agree to be audio-recorded  Yes  No  
 I agree to the use of direct quotations  Yes  No  
 I allow my name to be identified in any publications resulting from this study  Yes  No

**Introduction and Demographics**

1. Please indicate if you would like me to assign you a pseudonym, if you would like to choose your own pseudonym, or waive your right to anonymity and be identified by your name/surname.
2. Province or territory of residence
3. Gender
4. Sexual orientation
5. Age
6. Race/ethnicity
7. Your occupation
8. Education level

9. Marital/relationship status
10. How many years have you been working as a death doula?
11. About how many deaths have you attended?
12. As a doula, do you attend deaths in: Homes? Hospitals? Hospice care?
13. What is your fee range for death doula services?
14. Do you offer low- or no-cost services? Or services on a sliding scale?
15. Are you serving a specific cultural or religious group?

By signing this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

**Your Signature Confirms:**

- I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.
- I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.
- A copy of this Informed Consent Form has been given to me for my records.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

**Researcher's Signature:**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

\_\_\_\_\_  
Signature of Principal Investigator

\_\_\_\_\_  
Date

## APPENDIX D

### Canadian Death Doula Programs

| <b>Program Name</b>                                 | <b>Institution</b>   | <b>Delivery Method</b>                                      | <b>Tuition</b>  |
|---|--|---|---|
| BEyond [sic] Yonder Death Doula Core Skills Program | Virtual School of Deathcaring in Canada, Nova Scotia                       | Virtual Learning, twelve week sessions                      | \$2300 CAD  |
| Contemplative End of Life Care Certificate Training | Institute of Traditional Medicine, Ontario                                 | In person, five weekend modules over a five month period    | Full Program: \$1950 CAD + HST<br>Weekend Fee: \$390 + HST                  |
| Death Doula Training Program                        | Home Hospice Association, Ontario  | In person, three day sessions                               | \$500 CAD   |
| End of Life Doula Certificate Program               | Douglas College, British Columbia*<br>With trainings offered across Canada | In person, five day sessions (36 hours).                    | \$750 CAD   |
| Sacred Passage: End of Life Doula Certificate       | Conscious Dying Institute, Alberta   | Mixed delivery, 4 – 5 live Zoom sessions. 6 days in person. | Full Pay: \$2195 USD<br>Payment Plan: \$2495, four payments of \$623.75 USD |
| Soul Passage Death Doula Course                     | Soul Passages, Alberta   | Virtual learning, nine video lessons                        | \$249 CAD   |

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