

PHENOMENOLOGICAL EXPLORATION OF DEATH DOULAS
IN SASKATCHEWAN

A Research Practicum Report
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Abstract

The purpose of this research project was to explore and understand the emerging role, education, skills and services of death doulas in Saskatchewan. A review of the literature was conducted about community-based death care and the emergence of death doulas. A phenomenological research approach was used to interview 8 Saskatchewan death doulas. Commonalities were discussed as emergent themes in the data analysis process. As described by the participants, a death doula is a continuous presence at the end of life, offering non-medical support to empower, educate, advocate and build community around a dying person and their family. The participants also detailed the skills, education, and services provided by death doulas. Systems Theory was used to guide the discussion about the end of life care system in Canada and implications for social work practice.

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Dedication

Elizabeth Kubler-Ross once said “Those who learn to know death, rather than to fear and fight it, become our teachers about life” (Kessler & Kubler-Ross, 2007, p. 23). This project is dedicated to my parents, Rodney and Kim Karcha, who have always believed in and encouraged me to pursue a higher education. You have always been my greatest teachers. As a child I fondly remember learning to filet fish, bake bread and sew blue jeans. As I grew a little older, you taught me about the importance of family, taking care of aging grandparents and each other. When life handed our family the brutal news of dad’s terminal cancer diagnosis, you taught me how to face death head on with a sense of compassion and grace. With every year that passes, you continue to teach lessons about grief, family and love.

For this, I dedicate this report to you, and thank you.

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Chapter 1: Introduction

There is nothing inherently medical about dying. It's much larger than medicine. It is purely human. Part of the mission is to keep all of this couched in humanity. Not in medical science or social science, but really in the full arch of humanity itself.

Dr. BJ Miller, End Game (Sidewinder Films, 2018)

The purpose of this research practicum was to explore and gain an understanding of the role of a death doula in Saskatchewan. A death doula is defined by Cochran (2017) as

... a person who focuses on accompanying the dying and/or their families during the dying process; their unifying trait, regardless of special skills, gifts or particular calling is that they emotionally, spiritually and practically support the dying person until their death, although individual doulas may carry on their services after the death.

This chapter will begin with an introduction to the research project, a discussion of the theoretical approach utilized, as well as an identification of the research objectives. Systems Theory will guide the discussion throughout this document, recognizing that the average Canadian's cultural constructs related to dying and death have been largely impacted by macro systems including the healthcare system, funeral industry and policies related to end of life care. The chapter will conclude with a personal reflection of how this research project came to be, as well as a discussion about how I situate myself within the research project.

Introduction to the Research Project

Death is inevitable and will happen to each and every living person on earth. Statistics Canada (2019) reported 279, 936 deaths in Canada in 2018; these deaths occurred for a variety of reasons including cancer, chronic illness, injury, accidents or suicides. As will be discussed in the literature review, the majority of Canadians will die following a lengthy and predictable

decline from chronic illnesses such as cancer, heart disease, kidney failure or dementia (Fowler & Hammer, 2013). Kuhl, Stanbrook and Herbert (2010) studied what dying people want from the time they have remaining before their death, and concluded that dying people need: truth and reassurance; to be touched physically and emotionally; and time to come to terms with their illness, losses and unresolved issues. Hospice Palliative care, defined by the Canadian Hospice Palliative Care Association (CHPCA), is an approach to care that aims to relieve suffering and improve the quality of living and dying for patients and their families; striving to help them address physical, psychological, social, spiritual and practical issues (CHPCA, 2006). Research consistently shows the value of palliative care programming when it is accessible to dying individuals and their families (Giesbrecht et al., 2016; Cheng, Johnston, Lawand & Kelly, 2018).

Graeme, Downar and Morrison (2016) discussed the reality that palliative care is not widely accessible to all Canadians, and this shortfall of service provision creates large gaps in addressing end of life care needs for patients and families. These same authors discussed that end of life conversations are often sub-optimal due to healthcare providers' unwillingness to engage in discussions, lack of formal training for such conversations, and by barriers created by personal bias and beliefs about the importance of these consultations. The Canadian Hospice Palliative Care Association (2013a) supports these findings, indicating that as few as 16-30% of Canadians will have access to palliative care programs where they exist, noting that in many areas of the country there is no access to programs at all. In the absence of palliative care programs, a patchwork collection of programs and services, community resources, family caregivers and individuals often step in to address the unmet needs of dying individuals (Collier, 2011). More recently, as described by the Canadian Institute for Health Information (CIHI, 2018), the hospice palliative care movement has promoted an increased focus on building community capacity to

support end of life care, including increasing community-based resources and services.

Prominent palliative care physicians, such as Dr. Ira Byock, are encouraging communities to discuss death more openly and participate more in the care of dying people; sharing his message that social connections are often as important as medical treatment in preventing physical, mental and functional decline of patients (Byock, 2012). Increasingly, the healthcare system is looking towards the community for creative solutions to address gaps in palliative care services by encouraging a public health approach to end of life care (Kellehear, Shallnow, Richardson & Scott, 2017). As discussed by Russell (2017), a paradigm shift is occurring within the healthcare system to return the responsibility of caring for dying individuals back to individuals, families and communities.

There is some evidence that the message about the importance of community care is influencing community-based options at the end of life. “*Community-based deathcare*” is a growing movement that has emerged in response to the needs and interests of Canadians who seek to re-engage with dying and deathcare in more meaningful and sustainable ways (Community Deathcare Canada, 2018a). Community Deathcare Canada is a non-profit organization founded by a group of volunteers and is guided by a mission, vision and values statement reflecting their purpose (Appendix A). The group describes that the professionalization of death and deathcare has limited the ability of Canadians’ to participate in the care of their dying loved ones and this has left them less able than previous generations to experience healthy bereavement. The organization aims to honor the innate wisdom that family members and communities have in providing care to dying loved ones, realizing that some guidance is needed to return this wisdom back to the community, where prior to the development of the healthcare and funeral industries, it was considered to be generational knowledge (Community Deathcare

Canada, 2018b). Marymoon and Shinbrot (2013) described that the movement encourages individuals and families to return to historical methods of caring for dying and deceased persons, such as providing hands-on care to a dying person, preparing a body for burial and participating in funeral rituals. Community Deathcare Canada includes a wide variety of people, some of whom are offering private services to assist individuals and families explore, understand, and prepare for death in a holistic and meaningful way.

One example of a community-based deathcare service emerging in Saskatchewan is referred to as the *death doula*. Nelson (2015) discusses that death doulas are a movement born from a community-based, volunteer driven approach that addresses non-medical needs of dying people who lack informal support systems such as family, friends or other community resources. Death doulas claim to help dying individuals and their families address their emotional, spiritual and practical needs throughout the dying process. There is a small but growing number of individuals referring to themselves as death doulas in Saskatchewan, offering services on a voluntary or for-profit basis. At the present time, this service is unregulated and does not have any professional oversight in the province. Very little academic and research-based information exists about death doulas and their role, education, skills and services. Therefore, this research project was created in order to develop a better understanding of death doulas and how they can impact end of life care in Saskatchewan.

Theoretical Approach: Systems Theory

The main theoretical approach applied to this research project was Systems Theory. Systems Theory explains human behavior as the intersection of the influences of multiple interrelated systems (Offer, 1999). Social workers utilizing this perspective believe that the individual, family, community, society and other systems are inherently interrelated and must be

considered when attempting to understand and assist the individual (Offer, 1999). According to this theory, all systems are interrelated parts constituting an ordered whole and each subsystem influences other parts of the whole (Simmons, 2014). In utilizing this theoretical approach, I sought to understand how the interface of micro (the dying individual and their family), meso (community-based supports) and macro (healthcare system, funeral industry and policy) work together to support individuals and their families. I also sought to understand the role of a death doula within each of these interrelated systems. Systems Theory will be further examined in Chapter 5 where I discuss how death doulas could potentially influence end of life care on micro, meso and macro levels.

Research Goals and Objectives

The goal of this research project was to explore and describe the emerging role of death doulas in Saskatchewan and seek to better understand the skills and services they provide to individuals and families at the end of life. The research was exploratory in nature due to death doulas representing an emerging practice with scant research available on the subject. A phenomenological approach was utilized to interview 8 death doulas about their respective roles, education, skills and services. Ethics approval for this project was granted from the University of Regina on December 6, 2017 (Appendix B). The research design will be explored in more detail in both Chapters 3 and 5 of this report. The objectives of this research practicum were as follows:

- 1) To increase personal knowledge/education about end of life care and services available to individuals, families and communities at the end of life.
- 2) To develop qualitative research skills by utilizing a phenomenological approach, incorporating field research, open ended interviews and data analysis.
- 3) To understand how community-based deathcare fits into social work practice.

Personal Reflexivity: Situating Myself

It is important for researchers to situate themselves within their research through personal reflexivity (Creswell, 2013). My interest as a social worker has always been focused on helping people at the end of life; however, a deeply personal experience in my own family truly led the way to this research practicum. It was important throughout this research project to regularly reflect on how my own experiences shaped my understanding of the data and to ensure that I was aware of any bias I may have carried into this experience.

I entered the field of social work knowing that I wanted to assist people facing complex medical conditions. Prior to completing my social work degree, I worked as a porter at the Saskatchewan Cancer Agency and was fascinated by the array of treatment options available to help individuals beat a cancer diagnosis. Advanced medical technology, such as chemotherapy, radiation, mechanical ventilation and tube feeds, are now able to extend life much longer than previously possible (Coberly, 2002). Working in oncology affords one a very special view of how medical technology can ward off death; I actually experienced very little death in my interactions with patients because those who discontinued treatments were no longer seen in the clinic. In the absence of witnessing these deaths, one could come to believe that death did not happen often and that modern medicine could cure everything. This is reminiscent of the traditional medical model, with the belief that disease can be easily assessed, objectively measured and labelled, and successfully treated. (Papadatou, 2009).

After graduating from the Social Work Program at University of Regina with a Bachelor's degree, I relocated to British Columbia and began volunteering at a local free-standing hospice home. Hospice is defined as a program where individuals in the last 6 months of life receive high-quality, supportive end of life care services such as a physician, nurse, home

health aide, social worker, chaplain and volunteers, often in an individual's home or a location such as a free-standing hospice home (Casarett, 2011). As a volunteer at the hospice, I saw the dying process unfold and witnessed the deaths of patients who could not be cured by medicine. I learned about a holistic approach called hospice palliative care that could provide compassion, comfort and dignity to the individual and family as dying occurred. The Canadian Hospice Palliative Care Association describes this as a team approach to meeting the client's physical, psychological, emotional, social, spiritual and practical end of life needs, as well as the family's needs (CHPCA, 2006). I fell in love with the hospice palliative care model and, upon returning to Regina, joined the Saskatchewan Hospice Palliative Care Association to advocate for its widespread use across Saskatchewan. Despite this innovative approach to improving end of life care, access to hospice palliative care is very limited in Saskatchewan and very few of the people who would benefit from it actually receive it.

In 2014, it came as a shock to my family when my otherwise healthy father was diagnosed with advanced kidney cancer. Suddenly, the tables had turned and I found myself on the other side, not as a social worker, but as a floundering family member. I distinctly remember the doctor explaining that "nothing could be done" and that the best option would be to enter into the palliative care program. The problem was that the only palliative care beds were in Regina and my parents lived in a small rural community over three hours away. I offered to move them into my home in Regina so they could have access to palliative hospice care services. My father faced his terminal diagnosis with a sense of openness, forwardness and practicality that was typical of him. He thought it over and said "take me home" to the community that he had lived in for his entire life; it was important to him to have the support of family, friends, the church and the community. We left the hospital with little more than a prescription and the hope that we

could figure out some way as a family to support him through the difficult journey that lay ahead.

Back in our home town we were fortunate to have home care services, a nearby hospital and the support of a talented palliative care coordinator whom we personally knew; the resources were limited but vital to our family. My mother, a continuing care aid by profession, was skilled in providing a great deal of the personal care required. We put a plan in place to deal with the medical aspects of his care, the equipment needed, the medications, the inevitable symptoms that would worsen, and the paperwork necessary for a home death. What was less concrete was how to address emotions, exhaustion, loss of income and rapidly changing family dynamics. The challenges were numerous and taxing. Overall, the medical system offered what it could in terms of symptom management; however, it fell short in addressing the emotional, spiritual and practical needs of our family. What made the difference in those dark days were the visits from family members and friends who came with food, flowers and stories. We looked at pictures and spent time reminiscing, even writing out my father's life story over tea and many tears. The United Church minister frequently stopped by and ushered our family out the door so he could have private conversations with my father. Without discussing it, by some innate way of knowing, the community swooped in and wrapped their arms around us. We also became acutely aware of the deep rooted death denial of some members of our social circle, those who stopped by with collections of herbs and stories of 11th hour miracles, or those who just stopped coming all together. A few short months later, just weeks after his 61st birthday, my father died in a rural hospital bed, pain-free, surrounded by those who loved him. Within the hour of his death, the funeral home had transported his body away. Two days passed and the next time I saw my

father, his body had been reduced to ashes in a simple red cedar funeral urn of his choosing. Holding that cold container in my hand was surreal and life altering.

I tell this story because this experience dramatically changed my view on end of life care and how I approach my interactions with dying individuals and their families in my current role as a social worker in a long term care home. I began my career with the intention of supporting people in working through complex medical systems and treatments because I believed these systems had the answers for clients. What I learned was that there are significant gaps in the current medical model of care and that it is very important to holistically address the needs of dying individuals and their families beyond their medical symptoms. Approximately 70% of Canadians will die in a long term care facility, hospital, intensive care unit or their private home without access to what is defined as hospice palliative care (CHPCA, 2015a). As a social worker, I know that the medical system can offer good pain control, life prolonging interventions and symptom management at the end of life. However, I also see large gaps in addressing clients' and families' spiritual, emotional and psychological needs during the end of life phase, including very limited bereavement follow-up for family. I continue to firmly believe that hospice palliative care greatly improves quality of life at the end of life; for this reason I continue to sit on the Board of Directors for the Saskatchewan Hospice Palliative Care Association and advocate for increased funding and access to these services for dying individuals despite their geographic location.

When I reflect upon my own family's journey, it becomes apparent to me that supporting someone through the dying process requires much more than the resources of the medical system. The role that the community played in supporting my family was instrumental; the most poignant memories I have are those from when support came dressed as family, friends, the

church and community. Without these informal supports our experience would have been very different and much more difficult. Rosenberg, Horsfall, Leonard and Noonan (2017) studied the relationship between formal (medical professionals) and informal (family, friends, community resources) networks for people dying at home; they concluded that informal care networks are vital, naturally forming, unique to the dying person and often operate separately from the formal care network. In my own experience, the informal network of care was crucial and available as a resource in our small rural community. However as a social worker, I know that many dying people have limited informal support networks to be called upon when needed. Sadly, many people do not have the family, private caregiver supports or financial means to cover the costs of dying in a location of their choosing (CHPCA, 2013b).

My personal experience (described above) led me to look at the role of the community in the dying process, particularly as it relates to supporting the emotional, spiritual and practical needs of dying individuals. I met a woman in Saskatchewan who called herself a “*death doula*” and our conversation sparked a deep interest in her role. She told me that she works with dying individuals and their families to create a holistic plan for their death and that she provides a continuous presence throughout the dying process. I was intrigued with the concept and set out to learn more about it. I quickly discovered that there is very little academic information available about death doulas and little evidence of knowledge about their training, skills or services provided. As a social worker, this lack of information sat poorly with me because death doulas are working with clients during a time when they are extremely vulnerable. To be honest, the “professional” in me felt somewhat leery of the whole idea at first and somewhat protective of the professional skill set needed to assist families at the end of life. However, I know from my

personal experience that informal supports can greatly improve the end of life care experience and that there is a great need for community-based support systems.

Summary

As discussed in this chapter, this research project was born out of a need to understand the emerging role of a death doula in end of life care and to seek to understand how this approach might relate to social work practice. I set out to learn more about the community's capacity to support end of life care and to increase my knowledge of available resources within it. With an open mind, I engaged with a small community of death doulas in Saskatchewan and interviewed eight of these participants about the roles, education, skills and services they provide. I was welcomed into their community and appreciated their willingness to share their knowledge and experiences with me. In the next chapter, I will review the available literature about death doulas and discuss their emergence in Canada.

Chapter 2: Literature Review

For more than half a century, we have treated the trials of sickness, ageing and mortality as medical concerns. It has been an experiment in social engineering, putting our fates in the hands of people valued more for their technical prowess than for their understanding of human need.

(Gawande, 2014, p. 231)

The purpose of this chapter is to examine the literature relevant to this topic in order to inform an understanding of the systems that have influenced the relationship that individuals have with dying and death, and to explore the emergence of death doulas in Saskatchewan. The literature review will begin with a brief overview of the significant factors contributing to the current relationship Canadians have with dying and death. The discussion will then introduce and explore the role of a death doula, an emerging community based service that provides emotional, spiritual and practical support to dying individuals and families. At the present time, very little research has been conducted with a focus on death doulas and their practices. The chapter will conclude with a comprehensive review of the history of death doulas, the philosophy of the care that they provide, and an exploration of available training programs for those wanting to become a death doula.

The Professionalization of Deathcare

In order to understand the community deathcare movement, it is important for the reader to understand the context that has shaped Canadians' relationship with dying and death. As described on the Community Deathcare Canada website (2018b), Canadians are experiencing the consequences of cultural alienation from death because they have accepted death to be medicalized and institutionalized. This section will provide a brief overview of the significant events and healthcare policies that have impacted the average Canadian's ability to actively

participate in the care of their dying loved ones. It is beyond the scope of this paper to provide extensive detail about the complete history of Canadian healthcare policy as it relates to dying in Canada; therefore, only a selection of the most relevant events are highlighted here.

1900s – 1950s.

As summarized by Northcott and Wilson (2017), during the first half of the 19th century, death was viewed as a common, normal and expected part of life. Life in colonial Canada was very difficult; a swift and painful death from malnourishment, infectious disease, accident or injury was commonplace. Death was a highly visible, ever-present fact of life because epidemics, wars, accidents, infection and childbirth claimed the majority of Canadians' lives (Arnup, 2013). There was also limited access to medical care, hospitals or doctors; therefore, family members were active participants in the births of babies and the deaths of loved ones (Northcott & Wilson, 2017). It was during this time that the societal attitude toward dying meant that people were well acquainted with death from an early age, and it was not shrouded in silence or mystery. Death was typically a community event, where extended family, friends and neighbors attended to the dying person and then participated in rituals such as joining the funeral procession to the place of worship and attending the funeral and burial (Arnup, 2013).

1950s – 2000s.

The second half of the 19th century was influenced by the introduction of improved public health policy and The Medicare Act of 1966. Butler-Jones (2009) summarized these changes and highlighted that significant improvements in mortality rates were attributed to the emergence of public healthcare changes and policies which brought things such as improved nutritional information, clean drinking water, sanitization practices, vaccinations, improved housing and antibiotics. Universal healthcare initiated publically funded hospital coverage for all

Canadians (Northcott & Wilson, 2017), and families could now bring their sick loved ones to the hospital for treatment of disease and symptoms of chronic conditions. The location of death shifted dramatically from the home to the hospital environment, with the numbers of deaths located in hospital peaking at 80.5% in 1994 (Wilson, Truman, Thomas, Fainsinger & Kovac-Burns, 2009). Canadians were now living longer than ever before and for the first time in history, death from chronic illness became the leading cause of death in Canada (Nagnur, 1996).

During this time period, advances in medicine increased dramatically, and medical technologies such as tube feeds, dialysis, cardiopulmonary resuscitation, mechanical ventilators and intravenous drips could now extend life well beyond what was possible for previous generations (Carlson, 2010). These treatments required admission to hospitals and could only be provided by trained healthcare professionals such as physicians (Smith, 2015). This meant that family members could no longer provide direct care to their loved ones and this instead became the responsibility of the healthcare team. Arnup (2013) described that as physicians became bolstered by advances in medical science, they focused increasingly on curative measures only, and death came to be viewed as a medical failure. By the mid-1980s, early hospice palliative care programs were initiated to provide care to the marginalized and abandoned patients that modern medicine had “failed” (Floriana & Schramm, 2012). Little emphasis was placed on pain control or quality of life and these patients often died alone in the hospital setting. Family members, particularly children, and the larger community support system were discouraged from being present at the deathbed during the time of death (Northcott & Wilson, 2017). Death, once a normal part of community life, now happened behind closed doors and was largely unwitnessed.

It was also in this time period that the funeral industry underwent a foundational change as the introduction of embalming practices and cremation services rendered it a professionalized

practice. Chiappelli (2008) reasoned that Canadians' desire for embalming and open casket funerals was largely related to a growing societal fear of death and the desire to present death in a way that was more aesthetically pleasing. Bodies were sent directly from the hospital morgue to the funeral home, rather than being kept in the family home. This change meant that community-based support such as visiting the body as it lay at rest in the home, washing and preparing the body, as well as other deathcare rituals, were lost. The professionalization of the funeral industry grew beyond the basic tasks of caring for a body to include an emphasis on laws, ceremony, ritual, and bereavement services (Bremborg, 2006). A study by Harrington and Krysnski (2002) concluded that the funeral industry continues to be the driving force behind funeral practices such as embalming, reasoning that the costs incurred as the result of preparing and dressing a body, corpse viewing, and selling caskets are fundamental to the economy of the funeral industry. All of these developments have served to further separate Canadians from dying and deathcare practices.

Due partly to the medicalization of death and the professionalization of funeral practices, families were no longer active participants in the care of their dying and deceased loved ones. Death, that had been common and familiar for the majority of Canadians, became unfamiliar and invisible from the wider community (Northcott & Wilson, 2017). People were no longer present in the dying process, and it became shrouded in mystery and fear. In contemporary western society, the death denial thesis has been advanced in the literature. It has been marked by research evidencing three key themes for Canadians: talking about death is taboo, attempts to avoid death through medicalization are made, and dying has been segregated from mainstream society (Zimmerman & Rodin, 2004). Martin and Tradii (2017a) discussed the argument that Canadians experienced the dissolution of traditional funeral customs, began using embalming or

cremation practices in an effort to avoid viewing the body, and developed a reliance on euphemisms to avoid discussing death in open and concrete terminology.

2000 –Onwards.

The early part of the 21st century saw a significant shift towards deinstitutionalization of healthcare. As described by Bernier (2003), reductions in healthcare spending led to decreased institutional services, such as hospital beds and physician numbers. The pressure on the hospital system meant that service delivery was pushed out of the traditional hospital setting and into settings such as homes, long term care facilities and private services. Heyland et al. (2010) described that moving death away from the hospital setting was an important step in normalizing dying and reducing the reliance on unnecessary medical interventions at the end of life. Deinstitutionalization effectively meant that patients, including the terminally ill, were sent home to be cared for by family members whenever possible (Arnup, 2013). However, families had not cared for their dying loved ones in a home setting for many years and this shift caused a significant increase in stress on the family unit (Rotkowski, Washington, Craig & Albright, 2017). The hospice palliative care movement began to grow in response to the increasing need to provide compassionate support to dying individuals and their families outside of hospital settings. The Canadian Hospice Palliative Care Association defines Hospice Palliative Care as “care aimed to relieve suffering and improve the quality of living and dying, striving to help individuals and families address physical, psychological, social, spiritual and practical issues” (CHPCA, 2013a, p. 6). This approach promoted a shift away from the prevalent western medical model to a holistic, patient centered, bio-psychosocial model of care (Papadatou, 2009).

In 2002, the World Health Organization extended the call for a public health approach to palliative care, which would emphasize integrating palliative care into all levels of the national

healthcare systems, with a focus on primary, community, and home-based care (Abdulaziz & Zahid, 2016). Hasson (2015) noted that it is essential to promote a public health approach in which comprehensive palliative care programs are tailored to specific cultural and social contexts. In its present state, hospice palliative care has adopted a public health approach to care, seeking to de-professionalize and de-medicalize end of life care, seeking to return it to the community and build up social capital that can then be mobilized when individuals come to the end of their life (Abel et al., 2012). Dempers and Gott (2017) discussed that many improvements to end of life care have been attributed to a public health approach and highlighted the importance of integrating palliative care into all levels of healthcare, particularly primary and community level care. The development of hospice palliative care has gently invited families back into the dying process, and has encouraged individuals and families to re-establish a participatory relationship with death.

Community-based Deathcare

As discussed in the previous sections, the relationship that the average Canadian has with dying and death has been largely influenced by macro level systems, including the medical system and funeral industry. Death was once viewed as a normal and expected part of life, and Canadians actively participated in the care of dying loved ones and post-death rituals such as body visitation, washing the body, and funerals. Medicalization and professionalization have had profound impacts on families, particularly in the western world where tasks such as death and burial have become streamlined and handled by professionals that do not personally know the deceased nor their families (Rolke & Moats, 2004). Although hospice palliative care has opened the door for Canadians to become more engaged with death, there is still a long way to go before death will be restored as a normal and expected part of life for many Canadians. Byock (1997)

discussed that cultural values and expectations must shift away from the denial of death and move towards understanding and accepting death as a normal and valued part of life in a community.

There is growing evidence that a public health approach is changing societal values about dying and death. Martin and Traddi (2017b) highlighted that Canadians are slowly experiencing a cultural shift that allows for more discussion and engagement with dying and death. This is particularly evident at a meso level (community level) where there is a growing number of organizations and activities related to changing cultural perceptions of death. Community-based deathcare is a growing movement and is focused on the idea that deathcare is both an ancient practice and an emerging contemporary idea. This represents a return to the notion that death can be handled at home by the family and local community (Community Deathcare Canada, 2018b). In addition to Community Deathcare Canada, other groups such as the National Home Funeral Alliance, the Canadian Integrated Network for Death Education and Alternatives (CINDEA) and the Green Burial Society of Canada have emerged to assist Canadians' with re-engaging with dying and death. These groups, through a variety of means, work to share the message that Canadians can become more involved and can be supported in caring for a loved one at end of life. Additionally, individual deathcare practitioners are emerging and offering private, community-based services, to individuals and families. Individuals have a growing number of options available to them. For example, they could seek a home funeral guide to assist them with holding a home funeral outside of a traditional funeral home or to locate a death café in order to have open conversations about mortality.

One of the increasingly known types of deathcare practitioner is a *death doula*, or *end of life doula*. A death doula is defined by Cochran (2017) as

a person who focuses on accompanying the dying and/or their families during the dying process; their unifying trait regardless of special skills, gifts or particular calling is that they emotionally, spiritually and practically support the dying person until their death, although individual doulas may carry on their services after the death.

The term is becoming more common-place and is being used more often in mainstream media including in news articles, popular magazines, on television and through social media representations.

Regardless of an increase in mainstream visibility of death doulas, it is important for the reader to understand that death doulas are not commonly included or described in the academic literature. For this project, I began by searching multiple search engines, focusing primarily on journals in the social sciences and medical journals. When reviewing the academic literature, search terms included: “death doula,” “end of life doula,” “community deathcare,” “death midwife,” “soul midwife,” “death journeyer,” “death supporter,” “death guide” and “family led deathcare”. The literature pertaining to “end of life care,” “palliative care,” “community engagement” and “needs of the dying” were also reviewed. Multiple search engines produced few results directly related to death doulas. To gather more information, it became clear that the grey literature needed to be examined. The term *grey literature* refers to information found in a variety of online forums, reports, news articles, podcasts, magazines, websites and training program materials. To gather more information, I also attended a 4-day course entitled *End of Life Doula Certificate* training through Douglas College when it was offered in Regina, SK.

The remainder of this chapter will describe the history of death doulas and their emergence in Saskatchewan.

The Birth of a Movement: History of Death Doulas

The term “*doula*” is an ancient Greek term that is defined as a female helper, maidservant, or female slave: a woman experienced in childbirth who provides advice, information, emotional support and physical comfort to a mother before, during and just after childbirth (Merriam-Webster’s Collegiate Dictionary, 2005). As described on the website entitled *Doulas of North America* (2018), the current role of a birth doula is to provide companionship, information, advocacy and emotional support; the role is non-clinical in that a birth doula does not diagnose, administer medications, or provide medical interventions. Birth doulas provide a holistic and non-medical form of support; she is there to listen and follow the wishes of the mother (Andreoulaski, 2013). By the mid-1970s, birth doulas were embraced by the public and they were active participants in the field of obstetrics, often present as labour coaches under the supervision of medical professionals. Research has provided evidence that the presence of a birth doula offers significant benefits such as improved birthing experience, strengthened mother-child bond, reduced usage of invasive medical interventions (Pascali-Bonaro & Kroeger, 2004) and overall reduced cost to the healthcare system (Koumouitzes-Douvia & Carr, 2013).

More recently, the term “*doula*” has been associated with those trained to provide non-medical support at the end of life (Corporon, 2011). Phyllis Farley is credited as first applying the term doula to the end of life process in 2000 after she attended the *End of Life Issues and Care Conference* in New York City (Trzeciak-Kerr, 2016). At the time, Farley was a chairwoman at the Maternity Center Association, a maternal non-profit organization, and she realized that the same hands-on help and emotional support that women received during birth would be equally beneficial during the dying process (Ackerman, 2017). Farley suggested that a

well-prepared volunteer could make a significant difference to those who would otherwise die alone. In 1998, she developed the pilot project titled “*Doula to Accompany and Comfort the Dying Program*” in conjunction with the Jewish Board of Family and Children’s Services and New York University Medical Center’s Department of Social Services. The program trained volunteers to serve those who had limited support from family and friends, to provide emotional, spiritual and social companionship to people near the end of life in hospitals, nursing homes, assisted living facilities and private residences (Doula Program, 2018). The program was a resounding success and gained the support of Dr. Robert Fines, head of Baylor’s Supportive and Palliative Care Services, at the Baylor Dallas Medical Centre. In 2006, the “*Doula to Accompany and Comfort Program*” was instituted at Baylor Medical Centre where the palliative care team screens and hand selects volunteers for the program. Volunteers are trained by professionals on topics such as: the stages of death and dying, grief and grieving, advocating for patient needs, comfort touch, compassionate presence, active listening, communication strategies, and spiritual and cultural beliefs at the end of life (Corporon, 2011). In 2012, under the leadership of Amy Levine, MSW, the Doula Program was re-established as a non-profit organization and continues to be a model for other in-house end of life doula programs across the United States. Based in New York, the program offers doula services to individuals in the community and hospital setting. The program has moved away from being government funded and now operates on grants or donations. To date, there have been over 400 doulas trained by their program, with approximately 50 active doulas providing no-cost services to dying individuals and their families.

Another important early influence in the death doula movement was Henry Fersko-Weiss, a hospice social worker who noted that there were many similarities between birth and

death, and that the care philosophies of birth doulas could be applied in a hospice setting (Nelson, 2015). In 2003, Fersko-Weiss pioneered a training approach for end of life doulas in a hospice setting that was based on the philosophies of a birth doula program he had recently completed. His program was designed to focus exclusively on planning for the last days of life, conducting a vigil, and re-processing the dying experience with loved ones post death. Emphasis was placed on the space around the dying person, and encouraged the use of touch, guided imagery and ritual during the dying process (Fersko-Weiss, 2017). In a podcast entitled *Death by Design* (Paul, 2018), Fersko-Weiss states “I really felt that I needed to hold onto the term doula, and use death doula or end of life doula to distinguish it from birth doulas, while still really honouring where this all came from.” His program is divided into three phases: 1) focusing on making meaning of a person’s life through life review and legacy work; and planning for the end of life; 2) conducting a vigil using a highly personalized, or person-centered, experience at the time of death; and 3) re-processing the death experience with family to establish positive memories and facilitate grief work (Fresko-Weiss, 2017). The program continues to be largely successful and Fresko-Weiss went on to create subsequent training programs for end of life doulas. This model provides the framework for most other doula training programs that have followed. In 2015, Fresko-Weiss went on to establish the International End of Life Doula Association (INELDA), a non-profit organization dedicated to training end of life doulas. Also it is the first organization of its kind offering optional certification for end of life doulas in the United States. Doulas can be certified by attending an INELDA training program, purchasing INELDA membership, completing an application and following several other steps including: completing work experience, processing evaluations, writing an essay exam, and securing

referrals (INELDA, 2018). Certification allows for doulas to be listed on a website with a public search option for individuals seeking the services of a death doula.

The two early influences, discussed above, have had a long lasting impact on the death doula movement. From its volunteer-base and grassroots beginnings, the role of a death doula has been to journey with the dying person and their family and to provide highly personalized services throughout the entire spectrum of end of life care. In her blog entitled *In Care of Dad*, end of life doula, Wolfson (2014), describes the roles of a death doula as someone who will explain the dying process to the family or loved ones, assist in creating a detailed “death plan” outlining the wishes of the person, provide companionship or respite services for the family, maintain a conscientious presence throughout the vigil, and assist the loved ones with re-processing their grief after the death.

As the death doula movement has progressed, death doulas began to provide services outside of the traditional hospice setting, aiming to deliver community-based information and support to those who choose not to, or were unable to, receive palliative care. Burgess (2017) described that death doulas provide information and services similar to those typically found in the hospice palliative care setting; however death doulas can provide these services without the constraints of hospital-based programs. As outlined by Casarett (2011), most palliative care programs are restricted to individuals who are expected to die within 6 months and have elected to forgo any further curative medical treatments. Death doulas can provide support to individuals who do not meet these qualifications or who are unable to access palliative hospice care programs in their area (Burgess, 2017).

In the United States there are presently many programs offering training for those wishing to become a death doula. Common topics within the programs include: communication

skills, deep presence, advanced healthcare planning, financial considerations, vigil planning, grief and bereavement, legacy work, celebration and ritual work, post death body care, and more. The majority of the programs offer a certificate of completion for course attendance, with an increasing number of programs offering “certification” for death doulas. Organizations in the United States, such as INELDA, Conscious Dying Institute, Quality of Life Care Doulas and Doulagivers are currently offering “certification” for individuals who train under their programs and use the term “certified death doula” as part of their promotional materials.

It is important for the reader to understand that certification of death doulas does not mean that death doulas are a regulated profession or overseen by a professional body in the United States, Canada or internationally. As summarized by the State Federation of Massage Therapy (2018), “certification” is the process by which private organizations recognize individuals for meeting certain criteria established by the private organization in which individuals are recognized for advanced knowledge and skills. It is a form of self-regulation which is *voluntary* in that it is not required of individuals prior to practice and is without governmental oversight. To date, self-regulated and voluntary certification of death doulas is the only form of oversight that death doulas have; there are no accreditation bodies, no regulating policies, and no governmental oversight of those practicing as a death doula. As discussed by death doula Cochran, “It is all very unofficial; at this time there are no federal or state accrediting agencies...and also no official training programs, requirements, or licensures for those striving to become professional doulas” (Nelson, 2015).

Canadian Death Doulas

In Canada, the emergence of death doulas has occurred at a slower rate than in the United States. In 2011, the first 2 day death doula workshop was offered at the *People and Progress*

Continuing Care Conference in Edmonton, Alberta. Nearly 400 healthcare professionals, caregivers and volunteers attended the conference and participated in how-to workshops designed to implement the Doula Program in their own hospitals, assisted living facilities or private residences. In an interview with the *Edmonton Journal*, the facilitator of the workshop emphasized that death doulas are compassionate companions who have a level of comfort with death, are trained in communication, and how to be present and fully available for the patient, their family and other support systems (Sands, 2011). In Canada, there are thousands of trained hospice volunteers providing services similar to the services encompassed within the role of a death doula. As described in the results of a 2016 Canadian Hospice Palliative Care Association volunteer training survey, these non-medical roles include support in several areas including: social support (provide friendship and companionship, share hobbies and interests, play cards or board games, read to the patient), emotional support (sensitive listening and non-judgmental discussion, holding a hand, being a quiet presence) and practical support (driving to medical appointments, running errands, provide respite for family caregivers) and others (informational support, religious/spiritual support and grief and bereavement support) (CHPCA, 2016). In a 2013 podcast, death doula Levine describes that the differentiation is that not all people have access to, or choose, hospice care and additionally there are many regulations regarding the care that is provided in a hospice setting, including time limits on life expectancy and the location of where services are provided (Sitar, 2013). Death doulas can provide services outside of the traditional hospice or palliative care program. They can become involved earlier than is possible in most hospice programs, and can be available in geographic areas that do not have access to these types of services.

Canadian-based training programs for death doulas are growing in number. The table below, provides a summary of Canadian-based death doula courses.

Table 1

Canadian Death Doula Courses

Course Name	Offered From	Delivery Method	Approximate Cost
Soul Passage Death Doula Course	Soul Passages, Alberta	Online delivery, 9 self-directed learning modules.	\$250.00
Beyond Yonder Death Doula Core Skills Program	Virtual School of Deathcaring, Nova Scotia	12 weeks or 250 hours of online learning + phone calls between students	\$2300.00
Scared Passage End of Life Doula Certificate	Conscious Dying Institute, Alberta	8 days of onsite learning, home study and a student practicum	\$2995.00
Douglas College End of Life Doula Certificate Program	Douglas College, British Columbia	4 days in person course	\$700.00
Death Doula Training Program	Home Hospice Association, Ontario	3 days in person course	\$500.00
Contemplative End of Life Care Doula Certificate	Institute of Traditional Medicine, Toronto	6 weekends of in person coursework and home study	\$2000.00

Similarly to what is happening in the United States, death doulas are presently unregulated in Canada. As a result, there is no professional oversight, third party governing or licensure involved. This can make it difficult to estimate how many active death doulas are actually in practicing in Canada; although Global News has reported that the profession is

growing steadily (Engel, 2016). In a recent Global News interview, death doula Matthews-Erimona estimated that there are 40 death doulas practicing in Saskatchewan currently, and that many rely on word of mouth referrals, personal websites and connections with other death doulas (Matthews-Erimona, 2018). Community Deathcare Canada encourages a community of practice model and holds public listings for over 60 individuals with varying interests in community-based deathcare, including 6 Saskatchewan listings. As described by Wenger (2009), a community of practice model is developed by groups of people who share a concern or passion for something they do and learn how to do it better as they interact regularly with each other. A disclaimer on the Community Deathcare Canada website states that they do not govern, guarantee, nor endorse the work of any listed practitioner and advise service users to explore the unique training, experience, skills and offerings of each person listed (Community Deathcare Canada, 2018a). Canadians seeking a death doula are required to find them through word of mouth referrals, personal websites or communities of practice; the onus is on the consumer to screen and select a death doula.

In Canada, controversy surrounding the terminology of death doulas have recently come to light. As described by Community Deathcare Canada (2018a), deathcare practitioners are not regulated and may refer to themselves by any number of titles. The Canadian Integrative Network for Death Education and Alternatives (CINDEA) has proposed the use of the umbrella term *death midwife*, defined on their website as a facilitator, who offers a continuum of direct and integrated guidance and support to the death journeyer and their family throughout a personalized and participatory pan-death process (CINDEA, 2018). Marymoon (2013) argues that there is currently a lack of clarity about what is expected and offered by various deathcare practitioners. “There is a need for a well-defined and easily recognizable term that would

identify someone providing a continuity of services throughout the entire process of before, during and after death” (Marymoon & Shinbrot, 2013). In 2016, the BC College of Midwives issued “cease and desist” letters to two “death midwives” stating that use of the term midwife is a protected by the Midwifery Act (Bains, 2018). Section 22 states that “No person other than a member or a physician licensed pursuant to The Medical Profession Act (1981) shall use the title “midwife,” or any word, title or designation, abbreviated or otherwise, to imply that a person is a member” (Midwifery Act, 1999, p. 12). In a recent article, the college states that CINDEA defies the Midwifery Act because the term “midwife” is a reserved title, and harm to the public is presumed from the breach of the law. The College is seeking a permanent injunction through the BC Supreme Court to stop death midwives from using the term “midwife” because it is exclusive to its members (Bains, 2018). At the present time the matter has not been presented through the courts and the CINDEA website continues to use the term and offer CINDEA recognition for death midwives who complete an application.

At the time of this writing, the End of Life Doula Association of Canada has established itself as Canada’s first organization offering voluntary certification and self-regulation specific to death doulas in British Columbia. Co-founders and death doulas, Jennifer Mallmes and Sarah Muxlow state on their website “Our mission is to raise awareness of the choices surrounding death, to provide quality training, to provide a community of support to death doulas and to provide resources and education to families and caregivers” (End of Life Doula Association of Canada, 2018). The group provides a code of ethics and standards of practice that its’ membership base is expected to uphold (Appendix C) and states that it will advocate for death doulas to be seen as part of the palliative care team. Mallmes has been involved in the development and instruction of the Douglas College End of Life Doula Certificate program,

described as a non-credited college certificate for those wishing to provide quality end-of-life-care to people who are dying and their families. The program description of the course describes that end of life doulas or death doulas are advocates for their clients and complement the work of the medical community and hospice-palliative care workers and volunteers (Douglas College, 2018).

Summary

Death doulas emerged in the early 1990s as a grassroots and volunteer driven practice that closely mirrored the non-medical philosophies of birthing doulas. This practice was developed in a hospice setting and has evolved to provide similar forms of emotional, spiritual and practical support for individuals who choose not to, or cannot access, the traditional hospice palliative care model. Death doula training programs are most frequently based on early teachings of Fersko-Weiss and include the components of: 1) focusing on making meaning of a person's life through life review and legacy work and planning for the end of life; 2) conducting a vigil for a highly personalized, or person-centered, experience at the time of death; and 3) working with the family to re-process the death experience to establish positive memories and grief work. There are presently a wide variety of training programs available, and multiple organizations offering a certification designation for their own particular program. It is important to note that death doulas do not presently have any form of regulation or overseeing body of any kind. In Canada, particularly Saskatchewan, the death doula movement has been slower to develop and is still considered to be a small, emerging and unregulated practice. The information gathered as part of the literature review in this document was used to develop the research project and formulate the questions used in the interview guide. The research project will be discussed in detail in the next chapter.

Chapter 3: Research Methods

The things that people learn purely out of curiosity can have a revolutionary effect on human affairs.

Fredrick Seitz (1997)

The purpose of this research project was to explore and seek to understand the emerging roles, education, skills and services provided by death doulas in Saskatchewan. A review of the literature pertaining to the professionalization of death, community-based deathcare and death doulas was conducted. The findings of the literature review were presented and discussed in detail in Chapter Two of this document. This chapter examines the methods that were used to conduct the research project and discusses the reasoning behind selecting these methods. This chapter will address methodological procedures including: research methods utilized, population sampled, data gathering methods, data analysis process, ethical considerations and study limitations. This discussion will provide the reader with the framework on which this research practicum was constructed.

Methods

The research methodology for this qualitative project was exploratory phenomenological research. At the beginning of this project, it became apparent that very little academic information was available about death doulas. As discussed in the literature review, death doulas are a new and emerging practice in Saskatchewan and little is known about them. The goal of the research project was to create a detailed description of the roles, education, skills and services of death doulas in Saskatchewan. By choosing exploratory phenomenological research, I was able to obtain a wealth of information from a small group of participants who refer to themselves as a death doulas.

Qualitative research.

For the purpose of this research practicum, qualitative research was the selected method of research. Creswell (2013) summarizes that qualitative research uses basic assumptions or interpretive frameworks to address the meaning individuals or groups ascribe to a social or human problem. To study a problem, qualitative researchers use a qualitative approach to inquiry; this includes: the collection of data in a natural setting sensitive to the people and places under study; data analysis that is both inductive and deductive; and the establishment of patterns or themes from the collected data. The final written report or presentation includes the voice of participants, the reflexivity of the researcher, and a complex description and interpretation of the data that was collected. Toscano (2015) discusses that qualitative methods are appropriate in social research, where such methods help the researcher understand the context in which participants act and these methods are essential to understanding people's experiences. By using qualitative research, I committed to using a method of research that would produce a wealth of detailed data about a small number of people referring to themselves death doulas in Saskatchewan. Qualitative research helps to develop a complex picture of the issue under study, in this case, to develop an understanding of the roles, education, skills and services offered by death doulas in Saskatchewan.

As discussed by Creswell (2013), qualitative research requires reflexivity of the researcher, or the requirement to view oneself as a data collection instrument and position oneself in the data. This means that a researcher will strive to convey how their background and experience shapes their interpretation of the data collected. As discussed by Finlay (2011), reflexivity helps the researcher to maintain a sense of openness to the world while being mindful of the impact of pre-understandings and assumptions that may impact on the research. However,

Patton (2012) cautioned that the credibility of qualitative methods largely hinges on the skill, competence and rigor of the person doing the field work. In the first chapter of this document, I shared my own experience of working as a professional in end of life care and how a close personal encounter with dying broadened my understanding of community-based deathcare. Throughout the remainder of this document, personal reflections and interpretations of the data will be incorporated. Researchers must recognize the importance of subjectivity of their own lens and acknowledge the powerful position they have in the research (Creswell, 2013).

Exploratory research.

As discussed in the literature review, very little research has been conducted about death doulas and their role in caring for the dying. Due to the overall lack of information available, the approach to this research was exploratory in nature. Shields and Rangarjan (2013) describe exploratory research as research that is conducted for a problem that has not been studied more clearly; the goals of exploratory research can include establishing priorities, creating definitions and developing goals for future research studies. Exploratory research is often used to gain insight and understanding into issues that are emerging, are not well understood, or are not well researched. It has been used in a number of end of life research studies to better understand non-medical aspects of care (Plescherger & Wosko, 2017; Wilkinson, Brown, Warwick & Akhtar 2014). As the sole investigator in this research project, the lack of formal literature was both a blessing and a challenge. It enabled me to start from scratch and truly enter into the research process with limited preconceived ideas of what I might find. The challenge I encountered was related to determining how to develop appropriate interview questions designed to truly engage and understand the experience of the death doulas when relatively little was known about their role.

Phenomenological research.

A phenomenological approach was selected for this research project because it allows a researcher to obtain descriptive data about a phenomena under study and identify commonalities about the phenomena. A phenomenological study describes the common meaning for several individuals of their lived experience of a concept or phenomenon (Creswell, 2013). Priya (2017) describes that phenomenological research often utilizes interviews or group discussions to collect data from participants and then identifies common themes or concepts, often referred to as the essence of their collective lived experience. The goal of this practicum was to explore and describe a new phenomenon in Saskatchewan, specifically the emergence of death doulas. As a researcher, I was particularly interested in understanding how the death doulas described and defined their experience. As described by Patton (2012), phenomenology helps to gain a deeper understanding of one's lived experience, how it is perceived, described, judged, remembered or talked about by others. Rather than giving casual, behavioral explanations, external theories or interpretive frameworks, the focus is on giving a description of the phenomenon as it is experienced by those who are being studied (Finlay, 2011). In utilizing this approach, the participants were each interviewed about their experience as a death doula in Saskatchewan and through a phenomenological data analysis process common themes emerged as the essence of their experience. Common themes among participants are used to help create a detailed description of their shared experience. Dahalberg (2006) discusses that an essence refers to a common thread woven through the variety of participants' experiences and makes up the essential characteristics of the phenomenon under study. Within phenomenological research, the participants are both the experts and the owners of the data that are collected. In order to engage in ethical practice with the participants, it is important to acknowledge that the participants are

the true owners of the data (Creswell, 2013). The participants in this study were offered the opportunity to review and edit their transcripts prior to any data analysis to ensure that the content accurately reflected their statements.

Phenomenological researchers often collect data in the field at the site where participants experience the issue or problem under study (Creswell, 2013). Information for this study was gathered through participation in the death doula community: including an online Facebook group entitled “Saskatchewan Deathcare”, by attending a variety of public presentations hosted by the participants, and through regular participation in a monthly peer coffee group with the death doulas. As a researcher I felt very fortunate and felt welcomed into the community as the participants were eager to share their experiences and knowledge. This allowed me to observe the networking of resources, discussions about future directions, sharing of knowledge, and interactions among the group members. For the purpose of this study, it was not necessary to observe the death doulas interactions with clientele and, therefore, no observations of this kind were made. Strega and Brown (2015) suggested that a key element of analysing the data is to *live* with the data, or to distance oneself during the analysis in order to clearly reflect upon it. Once the interview data were collected, I disengaged with the death doula community in order to focus on data analysis and reflection. In other words, I created a situation where I *lived* with the data during my analysis process, without possible influence from ongoing discussions and interactions with the research participants.

Bracketing, or *epoche*, is a process by which investigators set aside their experiences, as much as possible, to create a fresh perspective toward the phenomenon under examination (Creswell, 2013). As a researcher, I was required to bracket out my own experience and personal biases as much as possible. A central pillar of the Community Deathcare movement is “to

reclaim deathcare from the professionals and return it to the community” (Community Deathcare Canada, 2018b). In my reflective journal, which I kept as part of this research process, I wrote: “The word ‘reclaiming’ seems to signal a taking away or a taking back. It doesn’t sit comfortably with me as a professional who has spent years learning about grief and bereavement. There is an element of possessiveness and discomfort with that (December 2017)”. At times the journaling process was difficult, but very valuable in addressing my own biases through the project. As an employee in the medical system, it was necessary to acknowledge and attempt to bracket out those experiences through regular reflection and journaling. It is unknown to what extent, if any, my “professional” role impacted on the information shared by the participants. I was continually required to examine and re-examine how my own background as a social worker, and how my personal experiences with death, factored into my interpretation of the data.

Population Sampled

There were 8 participants who were interviewed for this study. Eligibility criteria for the study required that participants: 1) be over age 18; 2) speak English; 3) be practicing in Saskatchewan as a death doula; 4) have completed training as a death doula, and 5) be self-titled as a death doula. Participants were identified from: public listings on the Community Deathcare Canada webpage (1 participant), Saskatchewan Deathcare Facebook page (2 participants), word of mouth from other doulas in the community (4 participants), and self-referral (1 participant). As a researcher, I began by contacting participants from public forums such as the Community Deathcare Canada website and other online platforms such as Facebook. I also began attending a monthly peer support group hosted by the community of death doulas in Regina, SK in order to talk about the research. As word about the study spread, additional participants were recruited by

word of mouth referrals. Individuals who did not meet criteria were not included in the study.

Participant information is shown in the table below.

Table 2

Research Participants

Participant	Age	Gender	Course Taken	Fee for Service
DD01	64	F	Beyond Yonder	Yes for presentations to service groups. Volunteers services for individuals
DD02	48	F	Beyond Yonder	Yes for presentations to service groups. Sliding scale for services to individuals (approximately \$40/hour); volunteers services for clients who cannot pay
DD03	55	F	Beyond Yonder	Sliding scale for services to individuals, often volunteers services
DD04	49	F	Beyond Yonder	No fee for service at this time
DD05	29	F	Beyond Yonder	No fee for service at this time, would be willing to accept trades for service in future
DD06	57	F	Scared Passage End of Life Doula Certificate Program	No fee for service at this time
DD07	58	F	Beyond Yonder	No fee for service at this time
DD08	64	F	Contemplative End of Life Program: Institute of Traditional Medicine	No fee for service at this time

Data Gathering Methods

The primary data collection method used in this study was participant interviews. With input from the Academic Supervisor, Field Supervisor and the available literature, a skills and services checklist and interview guide was developed to explore the experience of the death

doulas. The participants were provided with the written materials for review prior to the interview, including: the consent form (Appendix D), demographic questions (Appendix E), skills and services checklist (Appendix F) and interview guide (Appendix G). Participants were guided through demographic questions and a skills and services checklist prior to the interview questions being asked. The interview guide included open ended questions with no forced answers. This allowed for the participants to elaborate and expand on any information that they wished to share. The same interview structure was used with all participants in order to ensure that the same basic lines of inquiry were pursued with each person interviewed (Patton, 2012).

Data Analysis Procedures

All of the interviews were conducted and transcribed solely by the researcher through listening to the recording and typing the transcripts verbatim. Although this process was time consuming, it was worthwhile in order to be able to understand patterns such as voice, humor, pauses and important content. Narrative excerpts are vital to understanding embodying the research and conveying meaning obtained from interviews (McCormick, 2011). Patton (2012) and Creswell (2013) both provide suggestions for phenomenological data analysis based on the work of Moustakas (1994), which include strategies such as: epoche, phenomenological reduction, horizontalization, meaning unit organization, textural description, structural description and composite description. Each of these steps are briefly discussed below.

As previously discussed, epoche is the process of setting aside one's own perspectives and biases; this was done throughout the data collection and analysis process in the form of reflective journaling. The first step in data analysis is phenomenological reduction, which refers to the process of reading the written transcripts several times to develop an overall feeling and understanding of them (Creswell, 2013). By reading the transcripts I was able to better

understand the essence of the participants' perceived experiences and begin the process of horizontalization. Horizontalization, as described by Moustakas (1994), is the process of examining and treating the data as all having equal weight and value at the initial stage of data analysis. In following this process, I created a list of equally weighted, non-repetitive statements from the participants. The interview transcripts were then analyzed for common content or meaning unit themes, described by Patton (2012) as sense-making efforts that take a large volume of qualitative material and attempt to identify common consistencies and meaning within (Patton, 2012). By doing this, common themes emerged from the participants' answers, and these themes included: *Roles, Education, Skills and Services*. Several subthemes emerged under each of these broad themes as well. The subthemes detailed and described the "what and how" of each unique theme. The subthemes are described in more detail in Chapter 4, using textural and structural descriptions and direct quotes from the participants. Finally, as described by Patton (2012), part of the analysis process includes the development of a composite description that synthesizes the data into an overall common meaning or descriptions of the lived experience of the group under study. The final data analysis is a composite description of the data.

Ethical Considerations

Ethics approval for this research project was granted by the University of Regina's Ethics Committee on December 6, 2017 (Appendix B). It is important to extend ethical considerations beyond gaining the approval from necessary committees. Ethics also includes sensitivity to vulnerable populations, power relationships and the purpose of the research (Strega & Brown, 2015). Although the population being studied was not deemed to be vulnerable, and the risk to participating in the study was minimal, I was mindful that the topic was sensitive in nature because many participants were sharing personal experiences with grief and bereavement. In

addition, as described by Stregra and Brown (2015), there was a need to be mindful of power imbalances, such as how, and for whom, the research could be used. As a researcher, I was mindful that this research could inform future areas of study or provide more concrete information about the roles of death doulas. It is important to note that this study only provides a glimpse into the current experience, recognizing that this emerging practice is evolving quickly and ever changing. The data in this study is only reflective of a small number of death doulas in Saskatchewan and therefore cannot be generalized to all practicing death doulas beyond this particular context.

As a researcher, I was committed to fulfilling all the ethical obligations of this research practicum. This included seeking informed consent, maintaining confidentiality and protecting the anonymity of the individuals. The participants were provided with an email copy of the consent form prior to the interviews, and this was reviewed with them again before the interview started. The consent form informed the participant of the purpose of the study, procedures, potential risk and benefits of participation, right to withdraw, and contact information for any follow-up. Additionally, once the data was transcribed I removed identifying markers from the data in an effort to further meet this ethical obligation. I was unable to promise total confidentiality due to the small sample size and the close relationships the doulas had as a community. I explained this to each participant and no concerns were raised.

Limitations

It should be noted that it is impossible to fully and completely remove my own personal interpretation in the analysis and interpretation of the data. To address this issue, many direct quotes from the participants are used to support the themes that emerged. I share these statements with the intent to support the data analysis and also to convey that the themes are a true reflection

of what was captured in the transcripts. Direct quotes are identified and discussed further in Chapter 4.

Summary

This chapter has identified and discussed the research methods used during this qualitative project. Exploratory phenomenological research was utilized to gather a large amount of information about the roles, education, skills and services of death doulas in Saskatchewan. The analysis of the data identified common themes and subthemes. These themes and subthemes are be discussed in greater detail in the following chapter.

Chapter 4: Findings

To practice dying in our culture is not often seen as safe or advisable. But if our culture was to recognize that death and life are inseparable, our approach to both might be quite different.

(Halifax, 2009, p. 198)

In this chapter, I will present the findings from an analysis of the eight interviews conducted with death doulas practicing in Saskatchewan. The purpose of the interviews were to: 1) explore the role of a death doula in community-based death care; 2) explore the education that the death doulas had received; 3) explore the skill set that death doulas have; and 4) explore the services that death doulas provide. The data will be presented in 4 sections, with emergent themes identified in the table below.

Table 3

Emergent Themes and Subthemes

Theme One: Roles	Theme Two: Education	Theme Three: Skills	Theme Four: Services
Supportive Role	Education is Important	Innate Wisdom and Skills	Pre-death Services <i>(Providing support, Making meaning, Planning)</i>
Continuous Presence	Interest and Personal Experience	Learned Skills	
Non-Medical Empowerment	Self-reflection	Ethical Practice <i>(Confidentiality, Roles and limitations, Working collaboratively with professionals, Knowing legalities)</i>	Active Dying Services <i>(The vigil, The family, Creating spaciousness)</i>
Education and Advocacy	Common Topics <i>(Communication, Compassionate presence, Being with a dying person)</i>		Post-death Services <i>(Rituals and celebrations, Grief and bereavement)</i>
Community Building	Certificate Not Certified	Personal Boundaries and Self Care	

The phenomena will be discussed in further detail under each subsection. The data will be presented using direct quotes from the participants to ensure accuracy of information collected.

Theme One: Roles of Death Doulas

The first theme that emerged from the collected data was Roles, with subthemes emerging of *Supportive Role, Continuous Presence, Non-Medical, Empowerment, Education and Advocacy and Community Building*. Each participant discussed that their role was primarily to be a support person, who stayed with a dying individual and their family throughout the dying process and provide non-medical support. Support was described as working to empower clients to become actively involved in their dying process, providing education and resources, advocating for increased service options, and building a sense of community around death by opening up dialogue and normalizing the conversations about death. The findings echoed information about death doulas that was obtained in the literature review process and reflects the values of the current community-deathcare movement.

Subtheme 1: supportive role.

The participants all agreed that the definition provided by Cochran (2017) adequately summarized the role of the death doula and captured that the role of a death doula is primarily a supportive role.

“When I read that, it was like, okay that is what I thought it was going into it.

Accompanying the families and the dying person, through the whole process and providing support.” (DD04)

“A death doula is someone who supports the family, and the dying person, in whatever way they need. Prior to, during and even after the death, on all levels like physical, mental, emotional and spiritual.” (DD08)

The participants identified that death doulas can offer a wide range of skills and services; however, most doulas have their own particular niche.

“A death doula can’t do everything, and we definitely see this with some of our teachers. People will focus on different areas. Some may have an interest in disposition or body care; others focus on celebrant skills; but no matter what portion of it they are doing, I always see it as a supportive role.” (DD04)

The doulas all identified that it is difficult to define a death doula because each person has unique skills, abilities and strengths.

“I think that it is a really important part of how we promote ourselves; we all have things that we are good at or things that we are comfortable doing. It is amazing to me that there are so many different pockets of it.” (DD03)

Subtheme 2: continuous presence.

The doulas indicated that a death doula can become involved with their clients long before the dying process begins and continue to be involved long after the death has occurred.

“I have a lady that I have been working with for almost a year because she has been living with terminal cancer, but she is not dying and she is still very well. Over the year, I seen her moving through the process a bit, but she definitely has a lot of questions about how to keep living.” (DD03)

The doulas identified that clients may seek services early on in areas such as advanced care planning, emotional or spiritual support, developing rituals or finding community-based resources. It was discussed that death doulas may begin to provide care earlier than typical hospice palliative care programs and can continue on afterwards as needed. Additionally, the relationship with a doula does not end when the death has occurred.

“It is not like you would say, “Okay family, this is over”; there is definitely a role of helping family members and guiding them through what comes next. You may have a lot of different people coming and going throughout the process, so you have someone navigating all that with you and providing consistency.” (DD04)

Subtheme 3: non-medical.

The doulas interviewed for this project emphasized that their role is non-medical because they do not offer the same services as those provided by healthcare providers such as giving medications, physically transferring the client, or personal health care.

“I want to say this, death doulas are non-medical. We are not there to do any of the medical stuff, so no meds, no shifting or moving the body, no nothing like that.” (DD02)

The doulas discussed the importance of collaboration with healthcare providers and in attending to the medical needs of clients.

“You are not there in a medical role at all; there is no giving medications or doing any of that sort of stuff. There are people who are there to do that; it is not your role or place.” (DD07)

For death doulas who come from a professional background such as nursing, it is important to be clear with their boundaries. One participant who has previously practiced as a nurse stated:

“I have to be careful that I’m not answering as a nurse, because I am not there in the role of a nurse and there are homecare or the palliative nurses that can do that.” (DD03)

Subtheme 4: empowerment.

The doulas shared an understanding that most Canadians and their families are largely removed from the experience of death because it primarily occurs in hospitals, long term care homes or funeral homes. Empowering clients to participate more in the care of their dying and

dead could be done through recognizing that the knowledge of this care was, at some point in time, ancestral or intuitive.

“What are our cultural norms now? It’s the funeral home and the medical industry. Thinking about taking care of the dying and dead, like our ancestors did, is now foreign to us because we never experienced that. The people who did that are now gone.”
(DD04)

The participants discussed that an important part of their role is normalizing death and empowering family members to intuitively participate in as much as they feel comfortable with.

“You can empower families by honoring the grassroots wisdom that we have as individuals and families to care for our dead. Kind of going back to the grassroots mentality of all this, because before there were the professionals, we did all of this work for ourselves.” (DD05)

Several of the participants discussed the importance of letting the client and family lead the way.

“There is a very, very delicate balance between empowering and disempowering; families can be disempowered if a person comes in too strong, too professional and or just starts taking over and not letting the family intuitively do what they need to do.”
(DD07)

Additionally, it was discussed that many clients will not want to do all of the care on their own; so in many cases it would be preferred for a death doula to work alongside professionals from both healthcare and the funeral industry.

“To have blended care now would be good, because it is a lot of work to take care of the dying, so to have that help now from the professionals is ideal.” (DD05)

Subtheme 5: education and advocacy.

The doulas identified their role as providing education and advocacy, either to individual clients or to the community as a whole. Providing public education and advocacy work were viewed as important in stimulating a cultural shift towards accepting death as a normal and expected part of life.

“People don’t know what their choices and options are, and if you don’t know anything, you don’t even know what questions to ask. Educating the public can start triggering those questions.” (DD08)

The doulas also highlighted the need to advocate for increased options for clients, including improved hospice programs, green burials and opportunities to learn about their legal rights for after death care.

“I think than we have an obligation to educate and to talk in public, to prepare people and get them talking. Right from home deaths, home funerals, home vigils and green burials, things like that are big trends. If that is what people want then we should be advocating for these change as well, right?” (DD06)

“A story that sticks with me is about a young woman whose father died and because everyone thinks you need to call the funeral home right away, the body was quickly taken away. When she wanted to see him one more time the funeral home said, we can do that for you but it is going to cost \$800. It is upsetting to find these things out, when people don’t know their rights.” (DD02)

The doulas agreed that not all Canadians are ready to re-engage with community-based deathcare practices, but that there is a growing curiosity among the public.

“I think what we are doing is putting down really deep solid roots, so that we can then help the broader community start asking those questions through death cafes, death dinners, group presentations and things like that.” (DD01)

Subtheme 6: community building.

The doulas identified the importance of working with others to increase the capacity in the community to talk about death and engage in deathcare practices.

“We need people around us to do this well; to truly feel supported so that a person can express the joy and the pain, we need to build a strong container around all this. We need to include this aspect of village making.” (DD01)

Several of the doulas discussed their role as a bridge between existing services and a continuous person that stays with a client. The participants identified that existing resources are important and needed.

“In our society right now, we have these strong pillars of resources, so call those the social workers, chaplains, palliative care nurses and doctors, and the funeral directors. The way that I see the role of a death doula is that we are the water flowing between those solid foundations. We offer the continued flow that helps the client go through all those resources and supports.” (DD02)

Additionally, the doulas highlighted the need to grow their own capacity as a community of death doulas. They discussed the importance of regular opportunities to meet, mentorship, debriefing with each other, and a Facebook page entitled “Saskatchewan Deathcare” as important to continuing to build their community.

“I think we need to support each other. It is helpful if you have a bit of a team; it gives us more to draw upon and to have emotional and intellectual support.” (DD06)

Theme Two: Education of Death Doulas

The second theme that emerged from the data was Education with subthemes of *Education is Important, Interest and Experience with Death, Self-Reflection, Common Topics, and Certificate Not Certified*. The participants had all completed a death doula training program prior to participating in the study. Participants were asked a series of questions about their courses, the topics covered, the most valuable lessons learned and the certificate they earned. Participants described their coursework as very meaningful to developing an understanding of working with dying people and developing a skill set needed to become a death doula.

Subtheme 1: education is important.

The participants in this study had all completed some form of training to become a death doula. They were in agreement that a training program and specific education is important to being considered a death doula,

“I think it is good to have some formal training. I’m not saying that anybody couldn’t do it, but in my experience in having done the training, it makes it something legitimate.”

(DD06)

“I’m not negating the importance of the draw, the curiosity, or the wanting to give back to the community because those are all good things. But how do we do that from a grounded place, a knowledgeable place and a competent place? It’s through education.”

(DD01)

One of the participants expressed her discomfort in forcing formal training and losing the grassroots-natural orientation but concluded that training should be required.

“If it’s about reclaiming what we already know and having this innate wisdom, and if this is truly community deathcare, then I struggle to answer this, I really do. Yet, if I was to

refer someone to a death doula, I would only refer someone who has had training.”

(DD03)

The participants identified that adequate training is important to being considered legitimate and knowing the roles, legislations, and expectations of a death doula.

Subtheme 2: interest and personal experience with death.

Participants were asked why they had decided to become a death doula. Several of the doulas revealed that they have always felt naturally comfortable discussing death.

“I have always been sensitive to death and intrigued by what it might be and I had this compassion for people at the end of life.” (DD02)

“It has always been there, just like following the spirit; I was attracted to it, not like a mental thing, but more a heart centered thing to be drawn to.” (DD08)

Others had experienced the death of a close loved one and felt compelled to learn more about end of life care in an effort to come to terms with their experiences and be better prepared for the future.

“It was all pretty heavy and pretty pivotal. I had no words, no language for any of this, so I started with some active research into how I could incorporate death more meaningfully into my life.” (DD01)

“Those were such profound experiences and I know that a lot of people reacted with fear, but I felt like it was a real privilege to be there.” (DD04)

“I kept thinking, when we get through this I have to learn about this so that I will never feel this helpless again and no one of my family will. It all stems from that personal experience of that helplessness, lack of knowledge and knowing there is a better way to do things but not being able to access it or figure out how to do it.” (DD07)

Whether it be through a natural affinity for end of life care, or close personal encounters with death (or a combination of the two), the participants all stated that they had achieved a personal level of comfort with death and that this was essential to the role of a death doula.

“We all have a willingness to approach end of life care and provide support.” (DD03)

Subtheme 3: self-reflection.

The participants in this study all stated that an essential component of any education program was self-reflection. Self-reflection is a method of examining one’s own assumptions, values and behaviors; it is an essential skill when working with others to ensure that personal bias or beliefs do not impact on decision making or relationships with others (Burr, Blyth, Sutcliffe & King, 2016).

“It is about really looking at yourself and your own comfort level with all of these things: death, relationships, the meaning of your life, where is your place in the universe?” (DD08)

“Death doulas need to have some sort of ease at being with death in their own lives before they can support someone else in this.” (DD02)

The participants identified that learning about their own ego and emotional triggers were vital to being grounded in the work.

“I think that when a person is grounded in their own sense of self, that they are more able to be with suffering without being consumed by it.” (DD01)

“Now when I’m working, I can see and I can catch myself, to say that’s a bias and just let it go. It is hard to exercise and understand this.” (DD05)

Some of the participants revealed that learning about themselves was both an enlightening and challenging component of the course.

“I was able to reconcile a lot of things on a personal level and that was profound for me.” (DD07)

“I was really challenged in the course, when it made me look at my own beliefs and thoughts on death; when I got right into it and I learned more about it, I realized I had to work on it individually and that really surprised me.” (DD03)

“Writing my own legacy letter to my family and children really made me sit with what it would be like to die” (DD02)

Subtheme 4: common topics.

The participants were asked to review their course modules and describe the topics that were covered in their course. Based on the analysis of the interviews and data collected in response to these questions, the common topics were summarized and are presented in table format (Appendix H). The participants were also asked what topics were most valuable to them:

“I am one of those people that find it all essential; I can’t say that any one of these things were more important than another. It was a very well rounded program.” (DD01)

Participants were asked to identify which components of their training program were most beneficial to them. The following three areas were highlighted as most beneficial: communication, compassionate presence, and being with a dying person.

Communication. Participants stated that communication was an important theme woven throughout their courses. Communication was described as deep listening, asking open ended questions and use of silence.

“A lot of people who are dying or grieving, people just aren’t listening to them. A lot of it is just learning to truly listen and be there for someone.” (DD07)

Compassionate presence. Participants discussed their role as being compassionate to the needs of the client or family through expressions of empathy, compassion and support.

“Being able to be completely present for somebody else is very important, whether it is the family or the client. Being able to set aside your own experiences, thoughts, ideas and opinions and be completely present in that space for that person and supporting by providing deep listening and presence.” (DD03)

Being with a dying person. The participants spoke of their role as being someone to offer support but not coming in with an agenda or a problem to solve. In being with a dying person, participants described their role as simply bearing witness to difficulties experienced by the dying person and their family.

“You’re not there to fix; there is no fixing death or grief because it is not a fixable thing.” (DD07)

“You just be present there and listen to pick up on where people’s fears and tears, and what festers for them.” (DD03)

Subtheme 5: certificate, not certified

Each of the participants had received a certificate upon completion of their training program; however, the participants all stated that receiving a certificate does not make them certified. The participants were aware that presently there are no overseeing bodies, regulating authorities, or accreditation levels for death doulas.

“It is a certificate of completion; you can say that you took this course and that you have done some training. But you are not a certified death doula; there is no such thing.” (DD04)

“It is like the little purple ribbon they give you in track and field, you know, for participating.” (DD05)

“There is no overseeing body to regulate what and who a death doula can be. I don’t understand how someone can be certified if you don’t have an overriding body that gives the criteria of what a death doula is.” (DD02)

Participants also voiced concern about some death doulas using the term ‘certified’, stating:

“It is a real misnomer to say “I’m a certified death doula” ... It gives the public a false sense of who we might say that we are. I think it’s better for everyone, for the public, for the medical people, for the registrar and other death doulas if we are very clear about that.” (DD01)

When discussing certification, the participants in this study identified that they felt conflicted about the need for regulation of death doulas. The identified benefits would include things such as being seen as a professional, providing legitimacy, providing protection, and maintaining standards. The identified draws backs included: dishonoring the innate wisdom, being seen as just another expensive service, and creating red tape and restrictions. The doulas voiced that some form of organization would be helpful to them; however, it may be too early to be looking at things like regulation. This would be a rich area of study for researchers wishing to learn more about regulation of death doulas.

“I think it needs time to grow; it’s still evolving and emerging at this point and it needs more time to develop.” (DD04)

Theme Three: Skills of Death Doulas

The third theme that emerged from the data was Skills, with subthemes emerging of *Innate Wisdom and Skills, Learned Skills, Ethical Practice, and Personal Boundaries and Self-*

Care. The participants described that skills of death doulas closely resemble the skills of many helping professions (Chan & Tin, 2012) and the importance of self-care and boundary setting were discussed as a healthy coping mechanism for conducting this kind of work (McGarrigle & Walsh, 2011). The participants were asked about the overall skills needed become a death doula; as well as the skills needed to provide emotional, spiritual and practical support to dying individuals and their families. Skills that were mentioned repeatedly in the data collection process have been captured and presented in table format in Appendix I.

Subtheme 1: innate wisdom and skills.

Several of the participants discussed that some of the skills needed to practice as a death doula are innate or natural.

“I don’t think people can really learn compassion, empathy or how to be authentic, vulnerable and genuine with people; some of that has to be innate.” (DD04)

“Some is it has to be just who you are; you have to have a general interest in death and learning more about participating more in it.” (DD03)

Another participant shared her belief that skills are honed with experience, and can only be learned by interacting with clients and gaining experience.

“It is about staying curious about life and keeping one’s heart open, putting yourself into situations that demand being uncomfortable and not averting the gaze.” (DD01)

“I think a lot of the skills you pick up by doing, or by making connections with others and by sharing what they have learned and this has tremendous value.” (DD07)

Subtheme 2: learned skills.

Several of the participants identified that education and training were key to skill development. Learned skills included being knowledgeable about legalities, financial considerations, teamwork, funeral planning, and grief work.

“You have to make sure that you are getting the right education and skills that you need to be able to help people appropriately.” (DD04)

“I think it is helpful to have an understanding about emotions and some techniques in being able to help people with their emotions.” (DD06)

The participants identified that their death doula education and other past training programs were important in having the appropriate knowledge base. The participants also all agreed that ongoing education was important and readily available.

“You acquire the skills through training; and there are other readings you can do on the internet or there are books galore.” (DD08)

Subtheme 3: ethical practice.

The doulas discussed that practicing ethically and defining a scope of practice is important, particularly because the clients that they serve are in a particularly vulnerable period of their lives.

“It is a real emotional, vulnerable and tender time. This is something that we need to look at in our communities of practice and need to be proactive about because there is a real pressure out there for us to be accountable.” (DD01)

At the time of the interviews, there was no overseeing body regulating the ethics and scope of practice for death doulas in Canada. Recently, the End of Life Doula Association of Canada published a Scope of Practice and Ethical Guidelines document (Appendix C); however participation in this Association is voluntary and continues to be unregulated. In addition to the

general concepts of “do no harm” and “good intentions,” the participants identified common components of ethical practice as: confidentiality, roles and limitations, working collaboratively with other professionals and knowing legalities.

Confidentiality. The participants discussed that maintaining confidentiality and obtaining consent are a very important features of ethical practice.

“I come from a profession where confidentiality is everything, so I always like to have that conversation right at the forefront and recognize that I am in people’s intimate space at a very vulnerable time to discuss very intimate information.” (DD03)

Roles and limitations. As discussed in a previous section, the participants felt that doulas each have their own niches and strengths in particular areas.

“You have to practice within the limits of your competence, and seek additional information, knowledge or support when you don’t feel confident or competent in what you are doing.” (DD05)

The doulas also discussed the importance of recognizing when a client or family would benefit from professional interventions.

“At times the pain is so huge, and I don’t profess to be a counsellor for sure, but I can help them to find the professional help that they might need.” (DD08)

Working collaboratively with professionals. The doulas discussed the importance of respecting professional boundaries and roles. It was identified that death doulas are not meant to replace any profession, but rather to work collaboratively with others to enhance options for dying individuals and their families.

“We have to be very mindful of that line and not overstepping or trying to invade other people’s territories. I definitely see a doula as being part of a team, because you can’t do everything obviously.” (DD05)

“We talked a lot about toe stepping and paying close attention to what the professionals around you are doing to find out where you fit in and how you can help out.” (DD07)

Several of the doulas identified tensions between death doulas and healthcare or funeral industry professionals

“We need to be reaching out to those strong foundational resources so that they know who we are and that will hopefully alleviate a little bit of the fear about what we are and what we do. I think there is a fear that people are doing this just to make money, or to replace, or to pretend that they are something they are not. I think people are starting to realize there is a place.” (DD02)

Knowing legalities. The participants identified that ethical practice included having a solid knowledge base about the legalities involved in Saskatchewan related to deathcare.

“People will ask you questions and you have to make sure that you have your background so that you are not doing something that you shouldn’t be doing and that you can help guide people.” (DD04)

“Some of the ones you need to be aware of like the Funeral and Cremations Services Act and Bylaws, the Wills Act, the Midwifery Act and regulations for your own city; knowing the laws makes it a lot easier because it lets you know what you can and can’t do.” (DD05)

Knowing legalities was discussed as important to ensuring that families were provided with adequate information to make informed decisions. In addition, it was discussed as

important to ensure that the death doulas themselves were operating within legal contexts and keep themselves free from any legal difficulties.

Subtheme 4: personal boundaries and self-care.

The participants identified that ongoing self-reflection and self-awareness was important in maintaining a sense of personal boundaries.

“I am pretty clear with my own self-awareness of when I’m off center and asking questions about why and doing what I need to do to fix that.” (DD01)

Setting personal boundaries around the work was identified as necessary to ensure the doulas were able to practice effectively. The participants identified setting personal boundaries around time, energy, number of clients, and involvement in community advocacy projects.

“It is about having the awareness to not let it take over, to not sacrifice your family or your own health. Because it could.” (DD04)

The participants identified that it is important to practice good self-care and a variety of self-care methods were discussed, such as yoga, meditation, smudging, physical exercise, debriefing with colleagues, taking breaks, and journaling.

“I do it and it really helps; it is something so small, but when I don’t do it I notice a huge difference. And when I do it, I notice a difference too, but in a positive way.” (DD05)

Theme Four: Services of Death Doulas

The fourth theme to emerge from the data was Services, with subthemes of *Pre-death Services, Active-Dying Services and Post-death Services*. The findings discussed in this section closely resembled the work of Henry Fersko-Weise, whose ground-breaking training program has set the bar for most of the death doula training programs available today. As discussed in a previous chapter, a single doula is not likely to provide all of these services, but rather some

combination of them. Some of the doulas discussed the benefit of teaming up with other doulas to provide services to clients.

“I shared this experience and some of the responsibility with another death doula and I found that it was really helpful to do that.” (DD02)

The doulas discussed that throughout the continuum of involvement, the services are largely dependent on the wishes of the client and family.

Subtheme 1: pre-death services.

The doulas identified that services in the pre-death phase vary widely depending on the needs of the client. Pre-death services could include journeying or companionship with the dying individual and providing individualized care that is unique to their particular needs.

“It is about companionship and journeying; pre-death to me is looking at the emotional, spiritual and physical needs of what they want and how they see this going and then to help achieve that with them.” (DD02)

“Ideally, you can help them articulate what they want before it gets to the point where they can no longer articulate it.” (DD06)

Three areas were discussed as important in providing pre-death services: providing support, making meaning, and planning.

Providing support. The doulas discussed the importance of providing support through journeying and companionship with the dying individual. The participants also discussed that a doula could help a person in addressing some of their regrets, unfinished business, emotional needs, and spiritual needs.

“It could be as simple as just being there to read to them, sing, do crafts or go for walks.” (DD05)

“It is about providing that support in a real non-judgmental way and keeping your own beliefs way back out of it.” (DD07)

“I had some really great conversations with her, the kind of conversations that I have never had before with any patients I worked with because I was never there long enough.” (DD03)

Making meaning. The participants discussed the importance of helping a client make meaning in their life, by participating in life review and legacy work. Legacy work was identified as a process of looking back on a person’s life and creating tangible memories such as writing a letter, making photo books, or sharing recipes.

“Legacy work is something that I really like, it is about creating something that he (son) will have to hold onto after she (client) dies.” (DD03)

“I try to help them honor their life, to find out what was meaningful and try to help them have a sense of legacy and a sense of what impact they have had on this life to help frame that with them.” (DD06)

Planning. The participants discussed the importance of planning in advance for financial considerations, healthcare wishes, expectations for vigil, and disposition wishes. Participants identified that a death doula could facilitate conversations about planning and guide clients in exploring their needs, making a plan, and arranging for appropriate resources. Several of the doulas discussed that they would write this plan down and use it as a guide to support the client and family when death became more imminent.

“It is about going through all that with people, it can be really helpful to get everything set up and it isn’t that easy to do.” (DD01)

“We can provide support and knowledge, maybe dispel some misconceptions and fears that come with death and do some planning for the logistics of it.” (DD03)

Subtheme 2: active dying services.

The doulas discussed that their role during the active dying phase is about responding to needs as they arise. The role during this time can vary widely depending on who is there at the end of the client’s life, such as family or friends. The doulas observe that people present and respond to needs accordingly.

“It is very fluid, you need to bend with what is happening and with what people need and where you need to step up.” (DD06)

The doulas discussed that in the active dying phase, the pre-planning would become active.

Three components of active dying services were discussed as: the vigil, the family, and providing spaciousness.

The vigil. The doulas described the vigil as the time of active dying, when the person is near death and the family has gathered and patiently waiting for the last breaths. The participants described that death doulas can provide information to the family, hold space for individuals to express their emotions, and normalize fears.

“It can be very scary for people who have never seen someone die before; a death doula will have knowledge about what this looks like and this can help people.” (DD07)

The participants also described their role as following through with the plan for vigil, by coordinating items such as music, comforting scents, lotions, and comforting family members.

“So I was there, I just had this presence, while they sat vigil for her 24 hours a day. I would spell them off a bit if they were all very tired during the night. They would sleep in the living room; her husband would crawl up into the bed with her, and I would put the

bed rail up so he didn't fall out. Knowing I was there and would oversee things helped them relax." (DD03)

The family. The participants identified that during the active dying phase, attention shifts to providing emotional support to family members, friends, and other supporters. The participants also revealed that they would assist in other tasks, such as walking dogs or doing chores, so that family members could stay with their loved one if that was what was requested.

"It about supporting the family and the people around them; a death doula can bring emotional support to any who is involved." (DD02)

Creating spaciousness. The participants discussed the importance of slowing down the process and encouraging family members to be as actively involved in the dying process as they wished to be. The participants discussed that immediately after death, families could be encouraged to spend time with the body, anoint the body with oil, or gently wash the body.

"It is about helping them with the emotional importance of honoring and grieving, and giving spaciousness and time to all of that so that they don't feel rushed or cheated in some way or cut off from their loved one." (DD01)

Subtheme 3: post-death services.

The participants shared that the services provided after the death has occurred would depend on the family and the plan that had been initiated in the pre-death phase. Services in this phase included helping families complete any required paperwork, contacting the funeral home or other resources, and following through with the relationship by providing grief support to the family. The doulas identified two areas of involvement for post-death services: rituals and celebrations; and grief and bereavement.

Rituals and celebrations. The participants stated that after a death has occurred, they may offer services in celebrations or other rituals.

“You just take your time to honor the body, and as you are washing you take the time to tell stories. You can introduce some scents that are lovely, touch, stories and memories and try to create some pleasant experiences to recall.” (DD06)

Several of the doulas discussed that they could provide services to plan home funerals or hybrid funerals with funeral homes; however, most stated that having the involvement of a traditional funeral home was still the most likely because most people have a level of comfort with that. The doulas discussed that it was important to understand the legalities involved in providing services, particularly as it relates to providing post-death services in Saskatchewan.

“The most problematic law, at this point, is that if a death doula is being paid for their services, they cannot touch the deceased body after the death in any way shape or form.” (DD01)

“If you are being paid you cannot touch the body, you can only direct the family in how to do it; so if someone says “Can you help me wash mom’s hair?” I couldn’t do that if I was being paid.” (DD08)

Grief and bereavement. The participants identified the importance of providing support to the family members in re-processing their experiences, or with grief and bereavement.

“Not everyone is going to need a grief counsellor; people find relief in family and friends and just letting them tell their stories over and over again. It is about being with them and saying I am here to listen. Death doulas facilitate a space to digest that grief as a family or a community.” (DD07)

The doulas discussed the importance of ongoing support for family members, including checking in with them at a later date for a follow-up visit. The participants also identified that it is important to refer family members to professional resources as needed. However, the participants described that while supports do continue after the death has occurred, there comes a time when the relationship closes.

“I never say that we will never lose touch, because realistically I cannot possibly stay in touch with everybody nor would I want to.” (DD03)

Summary

The data gathered in this study provided a rich and detailed description of the roles, education, skills and services of a small group of death doulas in Saskatchewan. As described by the participants, a death doula is a continuous presence, offering non-medical support to empower, educate, advocate, and build community around a dying person and their family. The death doulas interviewed for this study all participated in some type of training program that helped them develop their knowledge and skills. Death doulas offer a variety of services before a person dies, during the active dying process, and following the death. Services that are provided are dependent on the unique ability and skills of the death doula, and the needs identified with the client and family. The next chapter will discuss the research findings in more detail and will identify implications for end of life care services from a Systems Theory perspective.

Chapter 5: Discussion

The terminally ill, almost by definition, are among the sickest people in the health care system.

But dying cannot be reduced to a collection of diagnoses. For the individual and family, the enormity and depth of this final transition dwarfs the myriad of medical problems.

(Byock, 2012, p. 197)

The previous chapters of this document have examined the roles, education, skills and services of death doulas in Saskatchewan. This chapter discusses the findings and the implications for social work practice from a Systems Theory approach. Death Doulas are one small part of the much larger community-based deathcare movement and the even larger hospice palliative care system in Canada. Death doulas contribute an additional community-based support service and work to strengthen the message that individuals, families and communities play a vital role in end of life care. In this study, the death doulas discussed the importance of: promoting a cultural change around deathcare; striving to normalize death through engaging the community in dialogue about death; assisting individuals and families to take on a more participatory role in the dying experience; and working collaboratively with existing resources such as healthcare, the funeral industry and other community resources to improve end of life care. This chapter concludes with considerations for social work practice and areas for future research.

Systems Theory

Systems Theory is an approach to practice that explains that every system is typically understood as a whole made up of interdependent and interacting parts; this framework has been used since the 1970s to understand wider social changes in the field of social work (Payne, 2009). Bronfenbrenner (1981) proposed an ecological orientation model that suggests a person's

development and life experience is greatly impacted by the many interrelated, and interconnected, systems around them, such as their family, friends, community, organizational institutions and culture. As summarized by Sincero (2012), Bronfenbrenner's model suggested that individuals are influenced by interactions within five environments: the microsystem, the mesosystem, the exosystem, the macrosystem and the chronosystem. Each of these systems is discussed in the next section.

Michailakis (2014) suggests that modern society consists of a multitude of social systems and that the way each system operates, influences the experience and outcomes of social problems. Canadians facing death are impacted by complex interactions of their own values and beliefs, relationships with family, access to community resources, healthcare services and societal views of death. Chetkow-Yanoov (2014) described that most human systems are made up of interacting smaller units and also interactions with other larger units in their environments. Offer (1999) discussed that social workers who are engaged with dying individuals and their families must be knowledgeable about the social policy changes that have resulted in de-institutionalization and the promotion of care of the dying being moved to the community setting. The changes have resulted in both benefits and drawbacks for many Canadian families. Payne (2009) discussed that social work brings a whole system approach to dying, so it naturally incorporates family, community and cultural perspectives into the delivery of services.

The following section explores the role of death doulas in Saskatchewan using a Systems Theory based approach, specifically exploring how death doulas can have an impact on each system. Social workers analyzing the services of a death doula can utilize several key documents including the Canadian Association of Social Workers Code of Ethics (CASW, 2005a), the Canadian Association of Social Workers Ethical Guidelines (CASW, 2005b) and the Canadian

Hospice Palliative Care Association Competencies for Hospice Palliative Care Social Workers (CHPCA, 2015b).

Microsystem: individual.

The microsystem is defined as the direct environment of a person's life, or the system that immediately surrounds them, and this would include themselves and their immediate family (Sincero, 2012). Historically, the role of a death doula emerged to provide support to individuals who lacked other networks of support such as family, friends, and the larger community. Today, dying individuals may be isolated due to many factors, including: absence of family, distance from family, other obligations of family members, complex family dynamics, or because illness creates barriers for visitors (Sitar, 2013). The role of a death doula is primarily about supporting an individual through the dying process by providing them with a continuous, non-medical, compassionate presence. The doulas interviewed for this research project identified common themes of *Providing Support*: this included compassionate presence, journeying and companionship, *Making Meaning*: completing life reviews and working on legacy projects, and *Planning*: creating a holistic and highly individualized plan about how a person wishes to die, including spiritual, psychosocial and practical elements. Halifax (2009) discussed that resiliency to face end of life care challenges are greatly improved when individuals and families are able to be involved in the experience, are committed to planning for the future, and have open dialogue about their expectations. This aligns with the CASW Code of Ethics social work value of respect for the inherent dignity and worth of persons. According to this value, "social workers respect the unique worth and inherent dignity of all people and uphold human rights, including the right to self-determination and the client's right to make choices based on voluntary, informed consent" (CASW, 2005a, p. 4). Social workers can support dying individuals who wish to seek

services in the community to supplement their end of life needs, including the services provided by a death doula. This increases the client's autonomy, self-determination, and choice as they face end of life.

Mesosystem: family and friends.

The mesosystem involves the relationships between the microsystems in an individual's life (Sincero, 2012), such as one's family and/or close inner circle of friends and community members. Okun (2011) discussed that each family member will have a unique and varied reaction to a terminal illness, and that each reaction will influence others because a family is an interconnected and interdependent system. The death doula discussed that their second focus was on providing support to the circle of people directly around the dying individual, such as their family and friends. Research shows that there is a need for support to this layer because family members are increasingly called upon to provide emotional, spiritual and practical care (CHPCA, 2015b). Social workers see a need for increased support for the family. This aligns with the CASW Code of Ethics value of the pursuit of social justice. According to this value, "social workers believe in the obligation of people, individually and collectively, to provide resources, services and opportunities for the overall benefit of humanity" (CASW, 2005a, p. 5). Arnup (2013) discussed the importance of providing support to family and friends because each death in Canada effects the well-being of an average of five other people and may have significant and long standing emotional, psychosocial and financial repercussions for families. Stajduhar (2003) emphasized that, despite the difficulties they experience, a well-supported caregiver has opportunities for mutual reciprocity and finding meaning in the situation, helping to accept the impending loss, working through grief, and recognizing life-affirming aspects of the experience.

The services of a death doula are one of a growing number of community-based supports for families. Rando (2000) discussed that family members go through a process of anticipatory mourning, while at the same time having to attend to unfinished business, practical planning tasks and managing other obligations. The death doulas interviewed for this research project identified providing support to the mesosystem layer as *The Family*, stating that during the active dying phase the doula's focus shifts away from the dying individual and onto the needs of the family, or other supports including friends and community members. The doulas discussed several subthemes as important to providing support, including conducting *The Vigil*, when the doula oversees the plans of the individual and family around time of death, and assists with a wide variety of tasks. These tasks could include arranging a room, music, and scents. The doula also may incorporate *Rituals and Celebrations* to provide comfort before and after the death. The doulas also identified the importance of *Creating Spaciousness* to ensure that families had the time to spend with their deceased loved ones and space for *Grief and Bereavement*, or re-processing the experience with families to promote positive bereavement processes. Overall, the role of a death doula is to support the family and other people in the meso level, to take on a participatory role in caring for their loved one, throughout the dying process and afterwards.

Exosystem: community.

The exosystem is defined as the larger social systems that influence the individual indirectly through their interactions with the micro and meso systems (Sinceros, 2012). This may include healthcare professionals, the funeral industry and other community supports such as religious groups. As defined in the Social Work Competencies for Hospice Palliative Care document (CHPCA, 2015b), social workers build capacity in the community as a whole, with the belief that death and bereavement are social issues that require a collaborative community

response. The doulas in this study indicated that their role is *Non-Medical*; therefore, it was important that their client was receiving medical care from health professionals. Additionally, the doulas discussed that most clients would not want a full home funeral and burial, but that having a good relationship with a funeral home could assist the client in having a hybrid funeral or developing a personalized service with the help of a traditional funeral home. Therefore, the funeral industry and medical profession were still viewed as important contributors to the end of life experience. This aligns well with the CASW Guidelines for Ethical Practice for ethical responsibility to colleagues. According to this guideline, “social workers strive to relate to both social work colleagues and colleagues from other disciplines with respect, integrity and courtesy and seek to understand differences in viewpoints and practice” (CASWb, 2005a, p. 17). It also aligns well with the CHPCA Social Work Core Competencies for Hospice Palliative Care document that states “the interdisciplinary team in which social work practices brings together multiple perspectives, opinions and expertise to ensure holistic care for clients and families at the end of life and into bereavement” (CHPCA, 2015b, p. 18).

Importantly, the doulas discussed that *Community Building* was important at this particular level. The doulas who participated in this study stated that the development of good relationships among healthcare providers, the funeral industry and other community resources was important to successfully practice as a death doula. The doulas described that they are not meant to replace existing services, but rather to enhance options available in the community. The doulas discussed the importance of working *Collaboratively with Professionals*, and knowing their *Roles and Limitations* and *Knowing Legalities* about what a family can and cannot do at time of death, including required and official paperwork and disposition options. The doulas discussed that working collaboratively meant being aware of the roles of others and not crossing

professional boundaries, as well as educating healthcare professionals and the funeral industry about their role as a death doula.

Additionally, the doulas discussed the importance of community building within their own group, stating that knowing other doulas helps to develop skills and provides support to their growing movement. Developing their own community is being achieved through the development of a Facebook group and monthly peer-support coffee meetings in Regina and Saskatoon. It was recognized that there is future potential for the community to grow through the establishment of the End of Life Doula Association of Canada.

Macrosystem: culture.

Macrosystem is the term that refers to the actual culture of an individual (Sincero, 2012). The death doulas in this study discussed the importance of shifting cultural attitudes about death and dying through *Education and Advocacy*. Emerging research suggests that the western concept of death denial and death phobia is slowly changing (Zimmerman & Rodin, 2004). Although Canadians continue to be death avoiders, there is a growing interest in learning about death and mortality. Noonan, Horsfall, Leonard and Rosenberg (2016) stated that the improvements in death literacy skills, defined as a set of knowledge and skills that make it possible to gain access to understand and act upon end of life and death care options, has increased Canadians' abilities to engage with death. Individuals promoting community-based deathcare philosophies, such as death doulas, strive to develop death literacy through the sharing of information and resources. For example, there are some websites providing information on how to conduct a home vigil, including videos on how to wash and prepare a body for burial (CINDEA, 2018), and others that are providing details on the legal frameworks for family-led transportation of the body, post-death care, and disposition of bodies (Community Deathcare

Canada, 2018a). The death doulas in this study identified that *Education* and *Advocacy* were important parts of their overall role, stating that educating people about their legal rights and ability to participate in deathcare enhances the inclusiveness of families in end of life care and promotes positive grief and bereavement. The doulas discussed that education and advocacy are important components to promoting cultural change around dying and death. This aligns well with the CHPCA Social Work Core Competency document which calls on social workers to be advocates “Social work shall address clinical and policy issues at a mirco, meso and macro level of the healthcare system and in the broader community” (CHPCA, 2015b, p. 6).

Chronosystem: history.

The chronosystem includes the socio-historical contexts and shifts that occur over an individual’s lifetime (Sincero, 2012). The death doulas in this study identified that history has played a significant role in the relationship that Canadians have with death, and that the knowledge of how to care for loved ones who are dying was once common place. As discussed in the literature review, Canadians’ relationship with death has evolved from family-led care to professionalized care over the time period of the 1900s – 2000. Presently, a public health approach to palliative care is being promoted as the way forward (Hasson, 2015), where the success of a public health approach is found in changing the societal representations of death and the community’s response to it (Lessard, Leclerc & Mongeau, 2016). Prominent palliative care physician, Dr. Kellehear proposed an approach that combines the principals of health promotion and palliative care, suggesting that it had the potential to move life threatening illness, dying, death, and grief back into the public arena (Kellehear, 1999). He suggested that community-based care of the dying preceded institutional, professionalized care, and that restoring community ownership and social participation in death ‘as a normal part of life’ was desirable

and healthy (Kellehear et al., 2017). The approach is multifaceted and includes lobbying the government, creating safe spaces for discussions of death, increasing community-based supports for individuals and families (Kellehear, 2008), and promoting the idea that large networks of relations among people, professionals, teams and communities have the potential to be caring, enriching and rewarding for all parties involved (Abel, 2018).

The emergence of death doulas comes at a time when the overall healthcare system is focused on deinstitutionalization of care and hospice palliative care is promoting a public health approach and community-based care (Casarett, 2011). In many ways, the philosophy of a death doula is congruent with the existing messages of hospice palliative care and their emergence is a timely response to the call for increased community-based services. As discussed by Bosma et al. (2010) social workers are integral players in the development and delivery of end of life care services and will continue to be involved in the assessment and delivery of new services. This aligns with the CHPCA Core Competency of assessment that states “social workers assess clients and families and include comprehensive information to inform decision making and facilitate care delivery, with recognition that assessment is a fluid and ongoing process which reflects only the current reality of the client and family” (CHPCA, 2015b, p. 7). As a social worker, it is important to understand the societal context in which we work, assess new and emerging services, and provide comprehensive information to the clients we serve.

Future Directions: Considerations for Social Work Practice

Social workers have a long history of participating in the development of community-based programs and services. As discussed in the literature review, the early stages of the death doula movement were influenced by social workers and this movement continues to grow with many commonalities shared by the CASW Code of Ethics (CASW, 2005a). For example, the

death doulas consistently emphasized that confidentiality, consent, and client-led care are important features of their personal code of ethics. Confidentiality, informed consent and self-determination are considered pillars of ethical social work practice and are crucial to working with clients in vulnerable situations (CASW, 2005b). The emergence of death doulas is still in early infancy and has not yet reached a state of homeostasis; therefore, it is expected that continued change will occur as the movement grows and develops. The following considerations are put forth to the death doula movement based on a social work informed perspective to strengthen the movement.

Consideration 1: terminology.

The death doulas who participated in this study consistently discussed that receiving a certificate of completion did not make them “certified death doulas”. However, throughout the available literature, the term “certified” is used repeatedly in the advertising of programs and courses for death doulas. Particularly in the United States, many courses offer death doula certification through a voluntary, self-regulated, system offered by the trainer. This terminology is confusing and could be misleading for the individuals seeking to train as a death doula, and by the service users who may believe that “certification” means professional oversight. This language is problematic for social workers because it opposes CASW Code of Ethics value of service to humanity, where “social workers place the needs of others above self-interest when acting in a professional capacity and strive to use their power in ways that serve the needs of clients and the promotion of social justice” (CASW, 2005a, p. 6). It would be beneficial for the community-based deathcare movement to consider terms such as “certification or certified.”

Consideration 2: referrals.

The doulas in this study stated that clients primarily access their services through word of mouth referrals, online information, or specifically through the Community Deathcare Canada website. An emergent theme of this study was that death doulas offer a wide variety of services and while they have many commonalities, there are also individual differences between their roles, services, education and skill sets. The onus of assessing an individual doula's competency rests solely on the client during a time of high stress and vulnerability. This is problematic for social workers because it opposes CASW Code of Ethics, value of competency in professional practice, where "Social workers uphold the rights of clients to be offered the highest quality service possible and to demonstrate care for the client's interests and safety by limiting professional practice to areas of demonstrated competence" (CASW, 2005a, p. 8). The movement may wish to consider how death doulas are screened and clients access services to ensure that vulnerable clients are not disappointed or harmed by choosing the wrong service for them, or not understanding what service they are seeking among the wide variety of available services (for example "death doulas" verses "home funeral guides").

Consideration 3: development of oversight.

The death doulas identified that there is presently no regulating body, or at the very least independent overseeing authority, of death doulas in Canada or beyond. This also means that there is no established code of ethics or scope of practice that death doulas are obligated to adhere to. Overall, the doulas felt conflicted about the need for professional regulation of practice. They stated that there is a need for recognition of their education and skills, but also a desire to maintain their focus on community-based deathcare. As a social worker, it is concerning to me because there is no oversight or accountability for individuals working with this very vulnerable population. Lack of oversight opposes the CASW Code of Ethics, value of

integrity in professional practice, where “social workers demonstrate adherence, and transparency, in the values and ethical principles of professional practice” (CASW, 2005a, p. 7). As discussed by Marymoon (2013) the movement shares many commonalities with the emergence of birth doulas and midwives and it is likely that growth of the movement will follow a similar path in terms of oversight and regulation. While full professional regulation may not be required, or even desired, the death doula movement would likely benefit from some form of accountability. This is likely to eventually develop on some level, as is evident with the newly established End of Life Doula Association of Canada, where members will be expected to uphold a code of ethics and adhere to a scope of practice.

Consideration 4: equitable access.

The majority of doulas in this study were offering their services on a voluntary basis; however, some of the doulas were charging a fee for service or accepting gifts or trades. The amount of money that a death doula charges can range dramatically, as summarized by Brown (2015) educational workshops begin at \$20 a session and death doula services range from \$100 per hour to \$5000 for multi-day services. According to Neumann (2016), for those without the financial resources to engage with a doula, there is no alternative other than struggling alone or attempting to find someone willing to volunteer their services. Death doulas are not presently covered under any medicare or insurance system; therefore, the service is not widely available and only available to those that can afford to purchase it. This opposes the CASW Code of Ethics value of pursuit of social justice, which “upholds the right of people to have fair and equitable access to resources to meet basic human needs” (CASW, 2005a, p. 5). It will be important for death doulas who are charging fees for services to consider equitable access and affordability of

services for Canadians. The End of Life Doula Association of Canada (2018) would like to see doulas financially covered by public funds so that all who want to participate has equal access.

Consideration 5: emerging trends.

In Canada, the experience of dying and death is constantly changing in response to emerging treatment options, changing societal expectations, and shifting healthcare policy. As with all professions, death doulas will need to continually update and enhance their approach. One recent and major change in end of life care has been the introduction of Medical Assistance In Dying (MAID) in Canada in 2016, that allows for Canadians to legally end their life if they have met certain criteria. Otte, Jung, Elger and Klaus (2017) discussed the difficulty that practitioners can have with such requests, highlighting that the client's wishes often change. To be prepared for MAID requests from clients, death doulas need to understand the relevant legislation, legalities, available resources and personal bias towards MAID. At this time, ongoing education and training is not a requirement of a death doula, and this could mean that they are not trained adequately about emerging trends. This would oppose CASW Code of Ethics value of competence in professional practice, where "Social workers have a responsibility to maintain professional proficiency and continually strive to increase their professional knowledge and skills" (CASW, 2005a, p. 8). The community-based deathcare movement may wish to consider how doulas will be kept up to date and informed about emerging trends in end of life care.

Summary

In summary, the emergence of death doulas have come at a time when healthcare is focused on de-institutionalization of care and the development of community-based care options, particularly for non-medical care needs such as spiritual, emotional and practical tasks. Death doulas provide non-medical services to individuals and families to increase personal autonomy

and choice during the end of life phase, focusing on making meaning, leaving legacy, creating plans, and supporting the family. The death doulas were guided by the values of the community-based deathcare movement that encourages individuals and families to take a participatory role in dying and post-death care practices. The philosophy of death doulas aligns well with many social work values and their role has potential to address large gaps in care services, such as emotional, spiritual and practical supports. There are areas of improvement and potential development that the doulas may wish to consider as the community-based deathcare movement progresses, including paying attention to: terminology, oversight, a community of practice approach, equitable access to services, and emerging trends.

The goal of this research practicum was to provide a detailed description of the role, education, skills and services of a death doula in Saskatchewan. The project was exploratory, and therefore, no formal conclusions can be made and the results are not generalizable to death doulas as a whole. The project achieved its goal in creating a better understanding of death doulas and community-based death care. The research process also highlighted future areas of study that would be rich for continued study, such as, a deeper exploration of death doulas' perceptions of professionalization of practice. Future studies may also wish to include a focus on the perceptions of others, such as death doula service users and their family members, or other professionals involved in end of life care such as healthcare professionals and the funeral industry.

Chapter 6: Conclusions and Self Reflection

It is a simple but profound service – to grasp a fading man’s need for everyday comforts, for companionship and for help in achieving his modest aims.

(Gawande, 2014, p. 245)

Social work is a branch of the human sciences that seeks to understand human beings from a holistic perspective, viewing them as complex, multifaceted beings embedded in a multi-layered network of relations (Chow, 2013). As indicated in the literature review, the relationship that Canadians have with death has been largely impacted by the professionalization of the health and funeral industries; wherein, the average Canadian no longer participates actively in the dying process and the post-death care of their loved ones. In recent years, healthcare policy changes have resulted in the family becoming more responsible for providing care to their dying loved ones, particularly the social, emotional and practical aspects of care. The hospice palliative care model has been set forth as the ideal model of care as it seeks to provide holistic care for dying individuals.

The Canadian Hospice Palliative Care Association has provided information that positively supports the hospice palliative model of care; however, it is unavailable to the majority of Canadians because of the lack of services, fragmented care or geographic location. A public health approach to hospice palliative care integrates community resources into care provision for individuals facing the end of life. Through the completion of this research project, it was found that a growing movement is emerging called community-based deathcare. This movement strives to reconnect individuals and families holistically to the dying process and encourage active participation in deathcare. There are many forms of community-based deathcare practitioners offering services, including a new service provider in Saskatchewan

referred to as death doulas. A death doula primarily provides non-medical support to the individual and family before, during and after the dying process. They may provide assistance with addressing the spiritual, emotional and practical needs of dying individuals, often providing their support alongside the medical care team. This study applied a phenomenological research approach to explore the roles, education, skills and services of death doulas in Saskatchewan. The findings of this study provided a description of this emerging practice of death doulas in Saskatchewan. Commonalities were discussed as emergent themes in the data analysis process. The detailed description of the role, education, skills and services of a death doula has been presented in the findings. A Systems Theory based approach was used to explore the potential impact that death doulas may have on multiple interconnected systems, including: the individual, family, community, social organizations and cultural change. The discussion also included considerations from a social work perspective and areas for future research.

Final Self-Reflection

The completion of this research practicum was deeply moving in terms of its challenges and its rewards. To resituate myself at the end, I was required to look again at the beginning. At multiple points I was forced to self-reflect on my own education, personal experiences and comfort level with death. As a social worker, my training and education has been focused on how professionals of all forms are involved in end of life care, including music therapists, physicians, nurses, social workers and even trained volunteers. I continue to see great merit in having integrative, universally available palliative care for all Canadians. I appreciate the attention that the Canadian Hospice Palliative Care Association has placed on defining scope of practice and developing competencies for healthcare professionals in end of life care. There is no

doubt that having well trained professionals is essential in providing care for those individuals who need the support of palliative care.

However, the experience of my father's death forced me to consider what happens when individuals and families find themselves without these medical professionals. Unfortunately, the experience of my family was not unique, because the reality is, the majority of dying people in Saskatchewan will not have access to hospice or palliative care programming. This is not to say that they die poorly. Indeed the medical system is able to provide excellent symptom management and pain relief in most cases and in most locations. It is the other aspects of care that are lacking: the support to emotional family members, the need to prepare and plan for the experience of death, and the importance of creating spaciousness for family members to participate in post-death care rituals and be with the body. There is value in these things. The research demanded that I explore my own comfort level with community resources outside of the traditional medical system, and I was challenged to expand my notion of who can provide end of life care to vulnerable clients. At one point I had written "I don't believe that I would have ever even looked at this if it hadn't been for dad. I truly believed that palliative care had all the answers until it didn't for my family. This experience forced me to see something I had missed as a social worker practicing within the medical system. For a great number of people, the resources recommended do not exist in their area or are totally inaccessible (September 8, 2018)". In its absence, the community becomes an important source of support and independent services of many forms emerge to fill the gaps. Perhaps this is the greatest lesson I take away from the experience, an understanding that the community holds a great deal of knowledge and resources that can be mobilized to help families at the end of life.

For individuals without family or community support, death doulas have emerged as a source of support for dying individuals and their families. The community-based deathcare movement, and death doulas, is still in its infancy in Saskatchewan and many changes are likely to come in the future. There has been a tremendous amount of growth and change even in the past few months of this project. Death doulas provide a unique opportunity to increase personal autonomy and control for dying individuals and families. This is greatly needed and could be a valuable resource for those facing end of life. As the movement grows, it will be important for death doulas to consider how clients access their services, how services are overseen, and how to provide equitable access to services. It will also be important to consciously build relationships with the existing resources involved in providing care. These things are likely to come in the future and it is too early to say with confidence the direction the movement will go. Social workers can use the CASW Code of Ethics (CASW, 2005a), CASW Guidelines for Ethical Practice (CASW, 2005b) and social work theory and competencies to assess the value to community based supports such as death doulas when working with clients.

I am indebted to the women who participated in this research study and shared their time and information with me. I was a deeply moved by their willingness to participate in this study and their large breadth of collective knowledge about community deathcare. The compassionate reception I received was appreciated. I felt welcomed into their group and inspired by their commitment, expertise, guidance and support. At many points throughout this research, I felt that we were a meeting of two very different worlds and that both groups came away with a better understanding of how to support the dying clients in the center. The doulas are the true owners of this research data and I am hopeful that they can utilize it to spread awareness and understanding

of their roles, education, skills and services. This is my gift back to them for all that they have given me.

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Appendix A: Community Deathcare Canada

Community Deathcare Canada Mission, Vision and Values Statement

Source: <https://www.communitydeathcare.ca/>

Mission

We are co-creating a national community of practice that inspires and supports Canadians to engage holistically with dying and deathcare.

Vision

We imagine a culture where death is reclaimed as an honoured part of life.

Values

- We believe in the healing and transformative possibilities of a more intimate and participatory relationship with dying and deathcare.
- We acknowledge that families and their loved ones have the inherent wisdom and the rights, both moral and legal, to care for their own dying and dead with any guidance and support they may choose.
- We support meaningful and diverse alliances among individuals, families, practitioners, and communities to foster engagement in dying, death and bereavement.
- We promote deeply ecological principles and practices in dying and death care.
- We believe that death is a profound, mysterious and universal part of life, whose challenges present opportunities for loving and compassionate responses.
- We respect and acknowledge the diverse sacred memorialization and meaning-making rituals related to dying and deathcare.

We continue to evolve, and are excited about building a community of practice which supports and promotes community-centred deathcare in Canada.

Appendix B: Ethics Approval***Research Ethics Board Certificate of Approval***

PRINCIPAL INVESTIGATOR DEPARTMENT REB#

Carla Mitchell Faculty of Social Work 2017-193

TITLE: Phenomenological Exploration of Death Doulas in Saskatchewan

APPROVED ON: RENEWAL DATE:

December 6, 2017 December 6, 2018

APPROVAL OF:

Application for Behavioural Research Ethics Review, Recruitment Email, Consent Form, Demographic and Baseline

Information, Interview Guide and Guidelines for Field Notes

Full Board Meeting Delegated Review

The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions:

<http://www.uregina.ca/research/for-faculty-staff/ethicscompliance/human/forms1/ethics-forms.html>.

Laurie Clune, PhD

Chair, Research Ethics Board

Appendix C: Canadian Death Doula Association Ethics and Scope of Practice

End of Life Doula Association of Canada – June 14, 2018

Source: <https://endoflifedoulaassociation.org/death-doula-association-of-canada-scope-of-practice-and-code-of-ethics/>

Vision: To raise the standard of End of Life Care.

Mission: To promote high quality End of Life Care by setting the standard for the doula profession through membership and training based on need and recommendations made by the Ministry of Health, health authorities and outside agencies.

Statement of Values:

- In alignment with our Code of Ethics and Standards of Practice, we will welcome and embrace our strengths and our differences, encourage involvement and provide equal access to opportunities and information for all members and clients.
- We recognize the diversity of personalities and skills that comes with a person. We will be respectful and inclusive to all members and clients regardless of their identities.
- We will promote beneficence in care. We will promote good, prevent and remove harm.

Standard of Practice:

Scope:

- The End of Life Doula (EOLD) provides emotional, educational and practical support that empowers the client to make informed decisions regarding their end of life care. The Doula communicates in a respectful, non-judgmental, encouraging way so that the client's wishes can be heard and fully understood.
- To provide support and resources to primary caregivers and persons supporting the client.

Limits to Practice:

- EOLD do not and are not qualified to prescribe any treatment, perform medical or clinical tasks, distribute medication, or diagnose a client.
- If a Doula has qualifications in alternative or complementary modalities (such as nursing, massage therapy, etc.), she/he must make it clear that these are additional services and are not in the scope of practice of an EOLD.
- Clients and EOLD must recognize that doulas are there to advocate but never to make decisions or project their own beliefs on another person.
- If an EOLD finds that the client's needs are greater than the scope of training, referrals are made to the appropriate resources.

Continuity of Care:

- The Doula should make back-up arrangements with another doula to ensure services to the client if the doula is unable to attend the client due to other life obligations or the need for self-care. If the doula is discontinuing service to the client prior to the end of the agreed upon time, it is the EOLD responsibility to inform the client in writing, provide a replacement and/or refund of an agreed upon amount of money.
- This may be accomplished by: Introducing the client to the backup EOLD. Recommending another EOLD or other appropriate resources.

Training and Experience:

- A EOLD is required to keep up to date with Government and Health agencies policies, the resources available to them and their clients as well as trying to gain as much experience as possible.
- Completion of recognized EOL education program (to be determined by board).
- Demonstrate competency, by updating and submitting additional training every 2 years, and by engaging with other doulas
- Provide references up on request
- Provide a criminal record check every 2 years.
- Minimum experience of 40 hours prior to applying to DDAC, not retro-active, with a minimum of 3 clients.

Code of Ethics:**Rules of Conduct**

- *Propriety.* The doula will maintain high standards of personal conduct in the capacity or identity as an EOL doula. The doula should not accept monetary gifts that exceed over and above what is stated in the contract.
- *Competence and Professional Development.* The doula will strive to become and remain proficient in the professional practice and the performance of professional functions through continuing education, affiliation with related organizations, and associations with other doulas.
- The doula will act in accordance with the highest standards of professional integrity.
- The doula will abide by the law of the jurisdiction they are working in.
- *Health Authority:* The doula will abide by the code of conduct of the health authority, if employed as a doula under that health authority.
- The doula will avoid actions that may constitute as sexual or personal harassment.

Ethical Responsibility to Clients

- *Primacy of Client's Interests.* The EOLD primary responsibility is to his or her clients.

- *Rights and Prerogatives of Clients.* The EOLD should make every effort to foster maximum self-determination on the part of his or her clients.
- *Confidentiality and Privacy.* The EOLD should respect the privacy of the client and hold in confidence all information obtained during professional service. The only exception is if someone was in danger, going to cause harm or admission of a crime. If a client shares information that needs to be shared with an outside source, EOLD have a duty to report it in an ethically and respectfully way.
- *Obligation to Serve.* The EOLD should assist each client seeking support either by providing services or making the appropriate referrals.
- When the EOLD agrees to work with a client, his or her obligation is to do so reliably, without fail, for the term of the agreement or to provide an acceptable alternative to care.
- When setting fees, the EOLD should ensure that they are fair, reasonable and commensurate with services performed. The EOLD must clearly state the fees to the client, and describe the services provided, terms of payment and refund policies.

Ethical Responsibility to Colleagues

- *Respect, Fairness, and Courtesy.* The EOLD should treat colleagues with respect, courtesy, fairness, and good faith.
- *Dealing with Colleagues' Clients.* The EOLD has the responsibility to relate to the clients of colleagues with full professional consideration.

Ethical Responsibility to the Profession

- *Maintaining the Integrity of the Profession.* The EOLD should uphold and advance the values, ethics, knowledge and mission of the profession.
- *Community Service.* The EOLD is encouraged to promote the Death Doula Association of Canada vision of "Raise the standard of EOLC" by providing doula services at a reduced cost, if possible, or making appropriate referrals, as available or necessary.
- The Death Doula Society of Canada reserves the right to update the Standards of Practice and code of Ethics.
- The Death Doula Society of Canada reserves the right to revoke membership to those members not upholding the Standard of Practice or Code of Ethics.
- The doula has the right to work in a safe environment. The doula will report all unsafe work environments and/or concerns.

Ethical Responsibility to Society

Promoting general health. The doula should promote the general health and wellbeing of clients and their families.

Appendix D: Participant Consent Form***Participant Consent Form***

Project Title: The Emergence of Death Doulas in Saskatchewan

Researcher(s): Carla Mitchell, Graduate Student, University of Regina, (306)520-4171, karcha2c@uregina.ca

Supervisor: Dr. Nuelle Novik, Social Work, University of Regina, (306) 585-4573, nuelle.novik@uregina.ca

Purpose(s) and Objective(s) of the Research:

The goal of this research project is to explore and seek to understand the role of death doulas in Saskatchewan. Community-Centered Deathcare is a new and growing movement that strives to reclaim a participatory relationship with death by honoring death as an important part of life. Death Doulas are among a growing number of deathcare practitioners who share a desire to empower individuals, families and communities to become as actively involved in shaping their own end-of-life and post-death care.

The goal of this research practicum is to utilize an exploratory phenomenological approach to explore and describe the emerging role of “death doulas” in the field of contemporary community-centered deathcare. A phenomenological approach to research will attempt to explore and understand the death doulas’ perceptions, perspectives and understandings of the emerging field.

Procedures:

Participants (“you”) are asked to review and sign the Terms of Reference and Consent Form. The terms of reference outline the specific purpose, guiding principles, decision making process, data use and evaluation of this project.

Participants are asked to participate in the project through participant observation and interviews. Participants will allow the student researcher to observe their practice through available and appropriate opportunities, as

determined by the participant. Participant observation will not be done with clients present. Field notes will be kept by the student researcher throughout the observation process.

Participants agree to be interviewed 4 times regarding practice, education, skills and services. Interviews will be recorded, transcribed and analyzed. The 1st interview is to confirm eligibility and obtain demographic information. The 2nd interview will be an in-depth interview about your practice, education, skills and services. The 3rd interview is to review your transcripts as part of a “member checking” process. The 4th and final interview is to review the study results and offer feedback prior to dissemination of results.

The estimated time to participate is 4-6 hours

Potential Risks:

- No potential risks have been identified.

Potential Benefits:

- Participants will benefit from the study by sharing their experience and information; this has potential to influence the growing practice of death doulas in Saskatchewan.
- There are no direct, or financial, benefits for participants.

Compensation:

Participants will not be compensated.

Confidentiality:

- The participant’s identity is confidential. Participants are provided with a pseudonym once they agree to participate, and this pseudonym is used throughout the entire study, including during the dissemination of results.
- There are limits to confidentiality due to the nature of group activities, small sample size and recruitment methods.

Storage of Data:

- Data will be kept in a confidential and secure location for 5 years.
- Data will be destroyed after a 5 year period.

Right to Withdraw:

- Participation is voluntary and participants can answer only those questions that they are comfortable with. Participants may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Should a participant wish to withdraw, their interview data will be removed from the study and not considered to be part of the research. This includes all statements made in writing or vocally. Participants right to withdraw data from the study will apply until February 1, 2018 (date at which data has been pooled, etc.). After this date, it is possible that some results have been analyzed, written up and/or presented and it may not be possible to withdraw the data.

Follow up:

- To obtain a copy of the final report from the study, please provide email contact information to the student researcher. The research practicum report will be available for public viewing following final approval by the Faculty of Social Work, and the Faculty of Graduate Studies and Research at the University of Regina.

Questions or Concerns:

- Contact the student researcher or academic supervisor using the information at the top of page 1;
- This project has been approved on ethical grounds by the U of R Research Ethics Board on (December 6, 2017). Any questions regarding your rights as a participant may be addressed to the committee at (306-585-4775 or research.ethics@uregina.ca). Out of town participants may call collect.

Signed Consent:

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
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<i>Carla Mitchell, Student Researcher, Signature</i>	<i>Date</i>
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<i>Dr. Nuelle Novik, Supervisor, Signature</i>	<i>Date</i>
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A copy of this consent will be emailed to you and a copy will be kept by the researcher

Appendix E: Demographic Questions

Death Doula – Demographic Questions

Age:

Gender:

Location:

Employment:

Spiritual background or affiliation:

How long have you been a death doula:

Do you charge a fee for your services? Y/N, explain

Do you carry personal or business insurance that covers your role as a death doula? Y/N

Are you registered on Community Deathcare Canada website: Y/N

Appendix F: Skills and Services Checklist

Skills and Services Checklist

(*adapted from Canadian Network for Death Education and Alternatives)

Skills or services of a Death Doula	I provide these skills or services	Skills and Services of a Death Doula
		*Please note: this is not an exhaustive list of skills and services. You will have the opportunity to expand on these and other skills during the interview process
		Educates the public about the range of options for deathcare
		Works in partnership with the death journeyer (and family, palliative care team, etc) in a holistic and meaningful way
		Focuses on supporting the family's direct participation, as much as possible – but is prepared to take over when needed
		Acts as an advocate – with doctors, palliative care team, cemeteries, etc. to ensure that the death journeyer/family retain choice and control over the death experience
		Provides direct support to both the death journeyer and family – especially guiding the immediate after-death care – and continues support for some time afterwards
		Assists with developing and/or performing various kinds of ceremonies that may be desired before, during and after the death – including celebrations of life, wakes, funerals and/or memorial services, as well as any rituals that may spontaneously arise.
		Offers an empathic disposition and active listening skills to understand and support values and choices
		Provides the necessary equipment and or informs the family what they need to prepare (stretcher to move body, Techni-Ice, copies of certificates and or permits)
		Provide emotional support to death journeyer and family
		Assist with filling out advanced directives
		Assist with wills, financial planning, power of attorney
		Participate in laying-in wake or presence at deathbed and beyond
		Complete necessary forms, including death certificates
		Transportation of the body
		Preparation of the body
		Participate in funeral/memorial celebrations/rituals
		Provide grief and bereavement support after the death
		Provide community outreach through presentations and workshops
		Advocate with funeral directors, cemeteries and memorial societies about sharing services and options available
		Development of green burials practices

Appendix G: Interview Guide

Interview Guide

Today's interview will cover 5 topic areas, Community Deathcare, Education, Skills, Services and Future Directions. The goal of today's interview is to develop a detailed description of your role as a death doula. Please answer the questions with as much detail and descriptive words as possible. You will be provided with an opportunity to review your statements and make changes/additions at a future interview.

Community Centered Deathcare:

**Participants are provided with the Mission and Values Statement of Community Deathcare Canada. The purpose of providing this information is to ensure we are speaking the same language, as community deathcare has been called many things: pan-death, death positive movement, etc.*

- 1.) What does community centered deathcare mean to you?
- 2.) It wasn't long ago that people were more actively involved in the dying process and post death care of their deceased loved ones. Why have Canadians lost touch with the practice of community centered deathcare?
- 3.) What do you believe, has been the impact of losing touch with the practice of community centered deathcare?
- 4.) Do you believe that Canadians are ready to re-engage with death and community deathcare practices? Can you provide some examples?
- 5.) Deanna Cochran has defined a death doula as "a person who focuses on accompanying the dying and/or their families during the dying process. Their unifying trait, regardless of special skills, gifts or particular calling, is that they emotionally, spiritually and practically support the dying person until their death, although individual doulas may carry on their services after the death". Do you agree with this definition? Is there anything you would add or change?
- 6.) What is the role of a death doula in the Community Centered Deathcare Movement?

Your Education:

- 1.) What brought you to the field of community deathcare or more specifically, to becoming a death doula?
- 2.) Why do you refer to yourself a death doula, as opposed to other common terms in community centered deathcare such as thandoulas, end of life coaches, home funeral guides, death midwife or ceremonialist?
- 3.) What education do you have related to being a death doula?
- 4.) How long was the education program that you completed (hours, weeks, months, years)?
- 5.) What topics did you learn about and what was most valuable to you?
- 6.) Did you receive a certificate upon completion of the program? Does this make you a "certified" death doula?
- 7.) Do you have any other education/skills that complement your work as a death doula?

- 8.) Do you believe that completion of a training program should be required in order to call yourself a death doula?
- 9.) Is there a need for ongoing education and skill development as a death doula?

Death Doula Skills:

- 1.) What are the overall skills needed to practice as a death doula?
- 2.) What particular skills are needed to help clients emotionally?
- 3.) What particular skills are needed to help clients spiritually?
- 4.) What particular skills are needed to help clients practically?
- 5.) How does a death doula acquire these skills?
- 6.) What guidelines do you follow for ethical practice?
- 7.) How do you maintain healthy and clear self-boundaries and how do you practice self-care?

Death Doula Services:

**These questions will ask you about services before the death, during the death, and after the death*

- 1.) What services does a death doula provide before the death?
- 2.) What services does a death doula provide during the death?
- 3.) What services does a death doula provide after the death?
- 4.) What do you do in the event that an individual or family requests services that are outside of your scope of practice?

Future Directions:

- 1.) How do you see the role of death doulas emerging in Saskatchewan?
- 2.) Are there any laws or regulations that a death doula needs to be aware of in order to practice in Saskatchewan? Do any of these laws or regulations interfere with your current practice?
- 3.) How do you see your role as fitting in with existing services (i.e.: funeral homes, healthcare)
- 4.) Community centered deathcare is entirely unregulated. Do you believe that service delivery is best left unregulated? What is the benefit of leaving services unregulated? What are the drawbacks?
- 5.) Is there anything else that wasn't covered today that you believe is important in learning about what a "death doula"

Appendix H: Education and Training Common Topics

Table 4

Education and Training Common Topics

Education is depicted by numbers below:

1 = Beyond Yonder Virtual School of Deathcare

2 = Conscious Dying Institute

3 = Institute for Traditional Medicine

Common Topics in the Coursework	1	2	3
Self- Reflection: the course required the participant to closely examine their own experiences, beliefs and values as it relates to dying and death. This includes addressing ego and personal biases.	*	*	*
Communication Skills: the course required the participant to learn about effective communication skills including: active listening, open ended questions, use of silence and other communication strategies to facilitate discussions of dying and death.	*	*	*
Teamwork: the course required the participant to explore and/or engage with community-based supports such as funeral homes, hospitals/hospices, spiritual care supports, community counsellors, policy makers, etc. This includes addressing professional boundaries, appropriate referrals to community agencies and legalities.	*	*	*
Needs of the Dying: the course required the participant to learn about common needs of dying individuals, how to provide holistic/person-centered support and how to address the emotional, spiritual and practical needs of the dying person and their family.	*	*	*
Legacy Work: the course reviewed the importance of completing a life review or legacy work; offered strategies to creatively and compassionately achieve this.	*	*	*
Spirituality: the course required the participants to learn about soul care or spirituality, cross-cultural overviews of different belief systems, accessing trained spiritual care providers and comfort modalities to address spirituality.	*	*	*
Advanced Preparations: the course required the participant to explore the purpose of advanced care planning, the process of completing an advanced care plan and creating a detailed plan for the final days of life. This includes documenting this plan in written format, also called a vigil plan.	*	*	*

Financial Considerations: the course required the participant to explore financial considerations such as wills or estate planning, learn about tools/resources available and how to support the dying individual through the process of arranging their affairs.	*	*	*
Disposition Options: the course examined options of disposition, such as traditional funerals, cremation, green burials, and alternative forms of disposition. This includes understanding the diversity of cultural, individual and family needs.	*	*	*
Home and Hybrid Funerals: the course required the participant to explore family-directed after-death care, home funerals and alternatives, including legalities, logistics, transportation of deceased, proper body care, and rituals for home vigils. This includes working with funeral home services	*	*	*
After Death Body Care: the course required participants to understand the laws, ethics, risks and safety involved in temporarily caring for a body, for example ritual washing. This includes rights and choices as it relates to body care and advocating for family directed care as appropriate.	*	*	*
Greif and Bereavement: the course required participants to explore emotions, strategies for healthy grief and bereavement and supporting emotional expression. This included when to contact a professional for support.	*	*	*
Rituals: the course examined rituals and celebrations, including the principals of rituals, how to develop a ritual and the importance of using ritual to facilitate healing throughout the dying process and afterwards.	*	*	*
Demystifying Death: the course required participants to understand the societal impacts of death denial, understand what the dying process looks like and how to support individuals and families in understanding the natural process of dying and death.	*	*	*
Self-Care: the course required participants to explore strategies for self-care, including mindfulness, personal boundaries, ethical practice, and recognizing limitations. Self-care is viewed as important	*	*	*
Remuneration: the course explored remuneration of the death doula role, including offering support in creating a business, charging a fee for service or developing contracts.		*	

Appendix I: Death Doula Skills

Table 5

Death Doula Skills

Overall Most Important Skills Needed	Communication and deep listening skills, compassionate presence, self-awareness and ego-awareness, being emotionally grounded, being comfortable with discussing death, an ability to guide and support individuals and families, and knowledge of laws and resources
Skills to Emotionally Support	Self-emotional management, empathy, caring, gentle approach, ability to hold space, meeting people where they are at
Skills to Spiritually Support	Respect for diversity, open-mindedness, non-judgmental, not imposing own beliefs, making connections with community spiritual care resources
Skills to Practically Support	Observational skills, willingness to learn, assessing needs, community building ability, and empowerment skills
