

Social Workers' Experience Working with Families with Children Facing Death

by

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Abstract

This study addressed the question: “What meaning do social workers give to their experience of working with families with children facing death?” Its purpose was to explore the meaning social workers attach to their unique professional role in this particular area of practice. Four social work participants from a children’s hospital were recruited, chosen because of their experience in working directly with this population. Criteria for inclusion were a minimum education level of a Master’s Degree in Social Work and at least two years of experience working in the hospital setting. A qualitative descriptive approach, drawing on phenomenology, was utilized. Each participant was individually interviewed for one hour using a semi-structured format. A phenomenological approach to data analysis was used. After careful review, four areas of meaning-making emerged: what brought participants to this work; meaning-making within the function of the role; connection and companionship; and, challenges faced within the role. These results add to the relatively small base of knowledge regarding the experience of social workers who work in pediatric end-of-life care in a healthcare setting.

Preface

All procedures of this research were carried out with adherence to the guidelines and ethical grounds for research involving human subjects presented by the University of British Columbia Behavioural Research Ethics Board. This research was carried out in collaboration with BC Children's Hospital and BC Women's Hospital and Health Center. Approval was granted under the certificate number H11-03146 by the Children's and Women's Research Ethics Board.

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1. Introduction

I was drawn to this research topic, meaning-making for social workers who work with families with children facing death, from a personal experience I had early in my social work career. As a social worker, I seek purpose and meaning in my work with others. One cogent example of meaning-making presented itself while I was working in an Emergency Room (ER) in a hospital in a small British Columbia city. A code 'pink' was called, indicating that a child had come into the ER needing resuscitation. As I entered the ER with my supervisor, we saw the parents of the child standing outside the trauma room visibly upset, emotionally and physically. I learned that a nine-day-old infant had been admitted for a respiratory condition from which he would not survive. This nine-day-old was actively dying. As I heard the words, I thought, how do you support a family as they watch their child die and at the same time hold yourself together? A selfish thought, but it was what immediately came to my mind.

My supervisor, a wise woman, asked a very simple question that addressed the most relevant issue: if we know this nine day old is going to die, how do we best serve this family? For her, meaning-making stemmed from helping create moments of connection and remembrance for them. My supervisor spoke to the doctor and asked for the parents to be allowed in the trauma room. We accompanied the doctor as he spoke to the parents and explained what was happening medically for the baby and then we were able to lead the parents into the trauma room and make them as comfortable as possible. The mother sat on the hospital bed as her son was put into her arms and she was able to hold her child as he died. Our work as social workers continued after the baby died. We sat with the parents, and were present to support them through the initial grief they faced after losing their son. We helped preserve their memories of their son by providing them with a memory box, taking a lock of his hair, and

stamping his footprint on a memory card. We walked them through the immediate practical needs associated with a death by informing them of the steps that would be taken, the funeral homes available and the paperwork that needed to be completed. All the while, we were present with the family as they began to cope with the death of their son.

Walking out of that room after having spent hours with the parents, I began to process what I had just experienced. My thoughts were that this moment would not be forgotten by these parents and would affect their entire world; that we, as professionals, would be forever remembered in this particular moment in time. What a gift to be a part of this raw moment in a family's life. What a responsibility to honour these families in their darkest hours. To be able to be present for a family experiencing this kind of grief and loss: what could be any more meaningful?

This experience did not only affect the parents, it affected the entire team of medical professionals who shared the ER as their occupational home. Through this experience, I learned that I want to work with children and families around issues of grief and loss. What else became evident is that social workers have a unique role in their work with families with children facing death. Due to the emotional nature of the work, it becomes necessary to find a sense of meaning that allows practitioners to sustain their passion as well as their ability to self-care.

My research aim in this study was to explore the meaning social workers make of their professional role working with families with children facing death. It is their professional role in the medical system that enabled them to work with this population group, and thus create meaning, just as it was my professional role that allowed me to be present with a family through their son's last moments. Although social workers' professional experience may influence how they cope on a personal level with death and dying, this is not the focus of my research; rather, I

set out to explore the meaning they give specifically to their professional experience working with families with children facing death.

This study drew on phenomenology as a theoretical framework. The importance of doing phenomenological research lies in the need to uncover the essential elements of a phenomenon (Wojnar & Swanson, 2007), and as such is critical to understanding the experience of this population of social workers. When we better understand the essence of the experience of social workers who work with families with children facing death, we can better support them to be fulfilled in their professional roles, become more intentional in their practices, and avoid burn-out, which directly impacts job satisfaction and retention.

In this thesis, I begin in chapter 2 by reviewing the literature, focusing on research in pediatric palliative care. In chapter 3, I will discuss the methodology of this research study. In chapter 4, I will speak to the main meaning-making themes that emerged in the findings. I will then discuss these themes that I believe are significant in chapter 5, the discussion. I will conclude the paper with a discussion on implications this study has on policy and practice.

2. Literature Review

Social work in pediatric palliative care is a valuable and growing field (Jones, 2005). With the purpose of refining my research topic, I began my literature review examining previous research and identifying the existing gaps in the area of social work and pediatric palliative care. I focused my review on research related to social worker in healthcare, social worker in end-of-life care, social work in pediatric end-of-life care, bearing witness, meaning-making, and self-care. I concluded my review by evaluating the limitations of the literature.

I chose these specific research areas because of their relevance to my research topic, social workers' experience working with families with children facing death. I began by reviewing the more general topic of social work in healthcare and worked towards the more specific area of social work in pediatric palliative care. Bearing witness, meaning-making and self-care were noted themes that surfaced from my preliminary review of the literature. As such, I reviewed literature in those particular areas as well.

2.1 Social Work in Healthcare

Social work is concerned with enhancing the well-being of people within their social contexts. It is a broad profession with diverse practices and reaches from the micro, individual level, to the macro, systemic level ("Social Work," n.d.).

Jones (2006b) described the services most frequently provided by social workers in healthcare as: "supportive counseling for the family, assessment of the family support structure, help with financial arrangements, concrete financial resources, and advocacy for families' needs, choices and desires" (p. 42). Within a healthcare setting, their functions often translate to the biopsychosocial approach, a balanced perspective that looks at the entire person in his or her environment (Berkman, 1996). Berkman (1996) explained that the social work role according to

this approach is to make in-depth psychosocial assessments, engaging the family and referring patients to appropriate support services. It has become commonly adopted in hospital settings as a result. Barnes and Hugman (2002) argued that “the positive effect of social work responses to contemporary social theory can be seen in the move away from a ‘problem’ focus to a ‘growth/strength’ focus, with intervention essentially controlled by the ‘client’” (p. 285).

Rushton and Beaumont (2002) explored the social work role within multidisciplinary teams in the larger system. The researchers argued that the multidisciplinary team is the most effective way of assessing need and providing professional services, and noted that social workers have always played an important part in multidisciplinary teams by bringing the social context into the team discussion. Peck and Norman (1999) described social workers as more likely than any other health care professionals to be challenged in their practice. They described the functions of the social work role as overlapping with other health care professions, pointing out that what sets social work apart is the approach that social workers take to their work, which is grounded in values, knowledge and theory. These values place an emphasis on self-awareness, client self-determination and a critique of society and methods by which social workers can intervene to address social problems.

2.2 Social Work in End-of-Life Care

End-of-life care is not a new area for social work practice. Social work has historically provided care for dying individuals and their families in a variety of settings (Taylor-Brown & Sormanti, 2004). Social workers are described as the hub of the interdisciplinary team that provides comprehensive medical and support services to patients facing death (p. 3).

Fauri, Ettner, and Kovacs (2000) looked at bereavement services in acute care facilities and listed important social work services that should be available to the families, including

making available a private meeting place for the family, arranging spiritual care, arranging a viewing of the patient who has died, counselling, referral to support services, and follow-up with the family after the immediacy of the event has passed. Meeting the patients' and families' identified needs was a key theme throughout the literature regarding the role of the social worker in end-of-life care (Hodgson, Segal, Weidinger, & Linde, 2004).

Bern-Klug, Gessert, & Forbes (2001) suggested that the essential role for social work in end-of-life is that of "context interpreter," meaning the social worker's role is to coordinate with other health professionals to ensure that the patient and family understand the medical prognosis (p. 44). They illustrated this point by exploring the benefit of the "big picture." If families develop a realistic understanding of the dying process, they are more likely to make decisions consistent with the patient's wishes regarding end-of-life experiences. Brandsen (2005) argued that "implicit in the notion of context interpreter is practice that is diversity competent, mindful of what is important to the patient and family with respect to cultural values and ethnic experiences" (p. 49).

2.3 Social Work in Pediatric End-of-Life Care

Although research in palliative care has increased steadily, very little research has been done specifically with children at end-of-life, so that pediatric social work in end-of-life care is largely understudied (Jones, 2006b; Kramer, Hovland-Scafe, & Pacourek, 2003). Jones (2006b) illustrated the importance of the social work role in working with children in end-of-life care: "It is because of the tremendous vulnerability of dying children and their families that the profession of social work is so uniquely situated to be of assistance" (p.59).

Like much of the literature on social work in end-of-life care, the bulk of the research for social work specifically in pediatric end-of-life care was about how the social worker must focus

on the psychosocial needs of the patient (Hodgson et al., 2004). Similarly, Jones (2006b) posited that, ideally, social work in pediatric end-of-life care encompasses five key roles:

“counselor/companion/guide, advocate/communicator/coordinator of services, resource broker, interdisciplinary team member, and ethical consultant” (p. 42). Her research acknowledged the experience of the social worker, which up until that point had not been formally explored in the area of social work in palliative care.

The role of pediatric social workers, as with the role of social workers with adults in health care settings, included facilitating communication between the family and medical team and coordinating care delivery (Jones, 2006b). Jones (2006a) found that although there was an identified set of needs faced by children and their families, needs varied depending on the particular family. What was most important was to meet specific needs as identified by and unique to each family, as opposed to addressing issues the social worker felt the family is facing (Jones, 2006a). Solomon and Browning (2005) found a positive correlation between physician-parent communication and parental assessment of care; “honest, straightforward information shared in the presence of a multidisciplinary team in a sensitive compassionate manner” is described as the ideal for families receiving difficult information, an ideal that is most often facilitated by the social worker (Jones, 2006a, p. 783).

The literature also points out that: “The pediatric oncology social worker, as a person, is as important as the information, skill, knowledge she possesses. The ability to be present, to witness and provide listening can be the best service available” (Jones, 2006b, p. 46). Browning (2008) argued that effective communication takes place when practitioners can move fluidly between expert and fellow human being. The illness and death of a child is one of the most difficult tragedies a family will ever have to face. What happens between families and their

health care team is vitally important in shaping how the family experiences this loss (Browning, 2008).

Most end-of-life care for children occurs in acute care and hospital settings, often in the pediatric intensive care unit (Carter et al., 2004). Meyer et al. (2002) found that health care professions often find pediatric intensive care units particularly difficult as our societal expectations for children's health outcomes are at odds with pediatric end-of-life care. As children are limited in their cognitive and emotional development, it often lands on the parents to determine the patient's best interests. Understanding the family dynamics is a necessary first step, a role often carried out by the social worker (Meyer et al., 2002). In pediatric settings, social workers provide services that assist both the patient and family in coping with illness, death and bereavement (Jones, 2006b).

Another aspect commonly explored in the literature is that of a parent's experience of having a child in palliative care. Konrad (2008) looked at mothers' perspectives on qualities of care in their relationships with health care professionals. Recognizing that for parents, feelings of loss and grief begin at diagnosis and carry through to the end of life, social workers are in a position to provide invaluable support for families with a seriously ill or dying child (Konrad, 2008).

Advocacy is a crucial element of social work. Many forms of advocacy are required when working with the families of children facing death and can include advocating for the child's voice, advocating for the family's sense of control, advocating for the medical team with the family regarding difficult medical decisions for the child, advocating for services and advocating for pain control for the child (Jones, 2006b). Overall, "the advocacy role is one of guiding the family; 'compassionate advocate, educator, and guide'" (Jones, p. 47).

Wolfe et al. (2000) found that for many children at the end of life, their disease continued to receive aggressive treatment. For families, it is vitally important to have a sense of control around their child's impending death. One way for children and their families to maintain control is to decide what the child's death will look like. Hospice for children is something that needs to be considered as an option for end-of-life, but unfortunately, dying children are often deprived of palliative care options due to the lack of coordination between interdisciplinary services (Carter et al., 2004). For example, Carter et al. (2004) found that 23% of patient records had documentation of an end-of-life discussion with the family but only one child received a hospice referral. The role of the social worker in facilitating communication within the interdisciplinary team is pivotal in these situations. Social workers are an integral part of a medical team and provide the entire range of social work assessment and intervention, sometimes for the staff as well as for the patients and their families (Jones, 2006b).

The most common ethical issue discussed in the literature is when children and their families do not agree with the healthcare team about continuing or stopping treatment: "Social work values of self-determination, empowerment, and starting where the client is, all speak to the important ethics of giving primacy to child and family in end-of-life decision-making" (Jones, 2006b, p. 59).

An additional theme that emerged is that communication with the caregiver after the child's death was vitally important to the parents and impacted their emotional health. Contact by clinicians after the child had died included sending cards, attending the child's funeral and providing various forms of assistance (Solomon & Browning, 2005).

The social work role in pediatric palliative and end-of-life care included less traditional interpretations of support as well (Jones, 2006b). Some themes in the literature included bearing

witness, meaning-making and self-care. The social work role in palliative and end-of-life care is to help the individual manage and cope with a multitude of complex feelings, “ultimately helping the individual to find meaning in death as they had in life” (Dane & Moore, 2006, p. 66).

2.4 Bearing Witness

Working from Jones’s findings on pediatric end-of-life care, I looked next at the literature for information regarding less traditional interpretations of support.

Bearing witness is, by definition, attesting to the authenticity of something through personal presence (Cody, 2001). The contemporary adaptation of bearing witness is a “call to listen to people, to be open to the reality of their lives, and to speak to their lives with a devoted fidelity to their experiences” (Cody, 2001, p. 288). Arman (2007) illustrated the ethics of care outlined by Cody (2001) by describing bearing witness as an existential encounter that, although it takes courage, alleviates a patient’s suffering. The significance of choosing to see and be witness to a person’s vulnerability and suffering with a humble attitude points to the immense challenge of daring to bear witness (Arman, 2007). Being present is also an essential aspect of witnessing; one has to be truly present and open in the moment. In healthcare, acute care environments commonly describe overwhelming workloads, a focus on medical model practice and a push towards the discharge of patients that limits human-to-human relationships, authentic presence and listening, which are the essence of bearing witness (Cody, 2001). If the healthcare setting does not support humanness in the care of patients and their families, social workers may be negatively impacted and rendered unable to be present for families in a time of need. Their skills may not be utilized and they may spend their time instead on discharge planning or managing a large caseload, which ultimately compromises the experience of families with children facing death. Solomon and Browning (2005) found that the greatest predictor for

families to cope ineffectively with the death of their child was the absence of staff at the time of death.

Arman (2007) spoke about existential or spiritual care; being there as a patient's witness can alleviate his or her feelings of suffering, but the person bearing witness will experience the emotional impact of sadness, grief and death, such that it requires courage to take on this role. Being a witness may bring a new understanding of life in the face of death and suffering: "The presence of a companion and a guide gives the patient an existential gift that preserves dignity and has the power to serve as a witness of eternal values in contrast to death" (Arman, 2007, p. 90). Cody (2001) also touched upon this topic: "Truthfulness vis-à-vis lived experience calls for a willingness to stand humbly before the mystery of life and accept the meaning that others have given to their experiences regardless of how these cohere or do not cohere with the meanings one has given one's own experience" (p. 293).

Respondents in Jones's (2006a) study on social work perspectives on the needs of children with cancer identified the importance of supportive counseling. One respondent explained, "families have a need for support, for people who have ability to sit with pain and just listen...emotional needs take forefront, helping them feel less alone and afraid" (p. 783). Konrad (2008) found that mothers of children who were seriously ill or dying value the willingness of professionals to be present with suffering.

2.5 Meaning-Making

Unlike the majority of the current research I found, which focused on the role of social work in regards to patient care (Berkman, 1996; Hodgson et al., 2004), Jones (2006c) looked at the meaning-making social workers use to represent their experience working with dying children and their families. Jones asked social workers who worked in oncology with dying

children, “How do you make meaning out of the losses that you face?” (p. 789). This exploration of social workers’ experience of finding meaning in their professional role is unique in the literature. Jones (2006c) presented her data in the form of a poem to best express the complex emotional experiences involved. Themes that were represented in the poem include social workers’ feelings of being “honored” and “blessed” to work with this population: “I have been given/a gift/It is the children I have known...I feel honored and blessed/ To have helped” (1-3, 12-13); an emphasis on easing pain: “hopefully/to ease their pain/in the process” (15-17); and being present for children and families: “I am able to be there/for the kids/and families” (34-36). Looking at the experience of the social workers themselves is valuable and gives insight directly related to my research question.

Although there are some similarities, dying children and their families are found to have needs distinct from those of adults. The role of pediatric palliative social work in end-of-life care offers social work an opportunity “to blend the unique professional skills of systems theory, family development, cultural awareness, and age-appropriate counseling with advocacy and program development” (Jones, 2006b).

Making time to be available, finding a quiet place to talk, maintaining eye contact, sitting instead of standing, and learning to be empathetic, all of these are important tools in the complicated and challenging endeavor of communicating well with children and families at the end of a child’s life. However, these tools will only do their job well if we understand and embrace the context in which we use them. Browning (2008) argued that social workers need to become good readers of children and families, and bring to that reading a full measure of respect, curiosity, humility, and reflection. We need to see parents as experts, because they know their children better than we do. We need to take a close look at our use of medical language and learn

how to break it down in order to meet families where they are. As Browning (2008) stated, “We need, above all, to be willing to show our humanness to children and families, just as they so readily show their humanness to us” (p. 28).

2.6 Self-care

As Jones remarked, “Pediatric end-of-life social work is challenging, multi-dimensional, fluid, emotionally intense, and contextual” (Jones, 2006b). Due to the emotional nature of the work, it becomes necessary for social workers to sustain their self-care if they are also to sustain their passion for the role of working with families with children facing death.

Social workers appear to be professionals suited to work within palliative care yet social work education has lagged behind in training them to work with individuals regarding issues of death and dying (Dane & Moore, 2006). There is an abundance of literature pertaining to education for social workers around end-of-life issues (Csikai & Raymer, 2005; Christ & Sormanti, 1999). Jones (2006b) found that social workers felt least prepared for pain/symptom management and medical discussions and yet in the literature this was clearly identified as a need (Solomon & Browning, 2005). Jones (2006a) found that physicians, nurses, and allied health professionals, including social workers, reported being unprepared to have conversations with children and their families at the end-of-life. Potentially due to the shift in social work roles in other areas of health care, and subsequent education related to those specific roles, the only task that social workers are being adequately prepared for in pediatric end-of-life care is, according to Jones (2006b), discharge planning. This theme suggests that there is a great need for further education for social workers in the area of pediatric end-of-life care.

Social workers also need outlets for managing the emotional toll of their experiences. Moore and Phillips (2009) discussed Schwartz center rounds, a multidisciplinary forum where

medical professionals come together to discuss and process the difficult emotional issues that can arise in health care. They found that attendance at the rounds resulted in increased insight, enhanced teamwork and decreased feelings of isolation in the context of clinical work. There are few outlets for health care professionals to process the emotional content of their days, yet it is such a critical piece of staying healthy for ourselves and our patients (Moore & Phillip, 2009).

I would like to comment on my frequent referencing of Jones in this literature review. Research by Barbara L. Jones, PhD, LMSW, Assistant Professor and chair and Co-Director of The Institute for Grief, Loss and Family Survival from the University of Texas, best reflects my area of interest. Dr. Jones has published several works focusing on pediatric oncology and pediatric palliative care. I found three articles by Dr. Jones to be of particular interest in relation to my research; the first surveyed oncology social workers regarding their role in pediatric palliative and end-of-life care looking at best practices for care of children and their families at the end of life (2005). The second article describes an exploratory study of social workers' perceptions of the psychological needs of dying children (2006a). The third article, which was a branch of the original study, speaks about the meaning-making of social workers in clinical practice with dying children and their families (2006b). I referred to these three works often throughout the literature review due to their relevance to my research topic.

2.7 Limitations of the Literature Review

There are several limitations with these studies. General gaps in the literature include the lack of Canadian content; I did not find any Canadian studies. Most of the research I was able to find was from the US and Australia. This is significant as most children die in hospital (Meye, Burns, Griffith, & Troug, 2002; Carter, et al., 2004), and the Canadian medical system differs significantly from other countries, most noticeably in in terms of financial obligations to families

as compared to the US. More specifically, there is very little information being gathered from the children and families themselves, leaving the interpretations of their needs to be constructed third-hand by the medical team. The existing research used quantitative or mixed methods and aimed for breadth rather than depth. There is very little literature about social workers' professional experiences. The one study by Jones (2006c) that looked at the topic, focused on social workers' meaning-making in regards to the losses they had experienced when children die in hospital, a very specific research question that could be expanded on easily by looking through a broader lens at the experience of social workers in pediatric end-of-life. The experiences of social workers themselves, rather than an examination of their role with children facing death, is a gap in the literature that warrant further exploration, as this study shows.

3: Methods

The purpose of this study was to gain knowledge about the essence of social workers' experience working with families with children facing death by exploring the meaning they make in this unique professional role. In this chapter, I provide an overview of the study's design, followed by a section on phenomenology, then an outline of recruitment and participants, data gathering, data analysis, ethics, and credibility, concluding with ethical issues.

3.1 Research Design

This is a qualitative descriptive study (Sandelowski, 2000) that drew on a phenomenological approach for exploring the experience of social workers who work with families with children facing death. A qualitative descriptive approach is described by Caelli, Ray and Mills (2003) as those studies that exhibit some or all of the characteristics of qualitative endeavor but rather than focusing the study through the lens of a known methodology they seek to do one of two things: either they combine several methodologies or approaches, or claim no particular methodological viewpoint at all. Qualitative approaches do not encompass a single universally understood position. Arising from multiple philosophic understandings of the world and the nature of humanity, there are many different standpoints from which to evaluate qualitative research (Sandelowski, 2002).

Qualitative research is a "situated activity and locates the observer in the world" and was chosen because it studies things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meaning people bring to them (Denzin & Lincoln, 2005). Qualitative research works well in exploring topics where little is known, gaining insight into phenomena, constructing themes to better understand phenomena, and ultimately helping create a deeper understanding of the phenomena (Morse & Richards, 2002). Qualitative research is

characterized by methods that are interpretative and that focus on meaning. Data collection is carried out in the natural setting and the depth of the data gathered is more important than the recruitment of large samples. Data analysis is an inductive process with the aim of describing and interpreting the range of attributes associated with the phenomena (Morse & Richards, 2002).

3.2 Phenomenology

This study drew on phenomenology as a theoretical framework. Phenomenology is an approach based on the philosophy that reality is constructed through a process where individuals give meaning to their experiences and subsequently respond to the reality they have created (Creswell, 1998). Phenomenology is often used in the social sciences as it considers the whole person and values a person's experiences (Connelly, 2010).

There are two main phenomenological approaches: descriptive and interpretive. As described by Connelly (2010), descriptive phenomenology was developed by Husserl and interpretive phenomenology developed by Heidegger.

Edmund Husserl, the founder of phenomenology, was primarily interested in the structure of consciousness and its relationship to the world (Sokolowski, 2000). Fundamentally, phenomenological research focuses in-depth on the essence of lived experiences (Rossman & Rallis, 1998). The basic philosophical assumption underlying this inquiry has most often been illustrated by Husserl's (1962) statement: "We can only know what we experience" (p.72). Therefore, no inquiry can engage in 'sciences of facts' because there are no absolute facts; we can establish only 'knowledge of essences,' particularly ways in which phenomena are perceived in everyday life (Moustakas, 1994). The essence is the central underlying meaning of the experience shared within the different lived experiences (Sokolowski, 2000).

Interpretive phenomenology, also called hermeneutical phenomenology, is based on the interpretivist assumption that humans dwell in the world with no capacity to be completely free of the world (Berthon, Pitt, Ewing, & Carr, 2002). Berthon et al. (2002) defined the hermeneutic approach as “a member of the social subjectivist paradigm where meaning is inter-subjectively created, in contrast to the empirical universe of assumed scientific realism” (p. 416). As part of the interpretative research family, hermeneutics focuses on the significance that an aspect of reality takes on for each individual (Berthon et al., 2002). In other words, social construction is a lens that molds individuals’ perceptions of the world and it is through this lens that meaning is created.

One of the main features of descriptive phenomenology is the use of a technique called bracketing or *epoche*, in which the researcher makes an attempt to suspend prior knowledge or belief about the phenomena under study in order to take a fresh perspective towards it (Creswell, 2007). In contrast, interpretive phenomenologists based on Heidegger (1996) explicitly believe that the concept of objectivity in research is erroneous. Importantly, Heidegger believed that bracketing experience is not possible, but rather, through reflective practice, we could become aware of our assumptions. Further, understanding comes from shared experience and meaning and in bracketing our experience we lose the capacity to understand it (Cohn, 2002; Heidegger, 1996).

For the purpose of this study, a generic descriptive approach drawing on interpretive phenomenology as a theoretical framework is used. As interpretivist phenomenology does not believe in bracketing, I set out my reason for interest in this research in the introduction to this paper with the understanding that it is that shared experience with the participants that gives me greater capacity to understand their experiences. It is also this same experience that impacts my

view of the world and thus my interpretation of the data. In this way, I am an active part of the research.

The study was completed in collaboration with a local hospital as a way to utilize purposive sampling by exploring the experience of social workers who have direct and specific experience working with children facing death; they therefore have an understanding of the central phenomenon of the study (Creswell, 2007).

3.3 Recruitment

For the purpose of this study, I recruited a total of five social workers by distributing my recruitment poster to all social work staff at the hospital. The hospital provided me with avenues for distribution of my recruitment poster both physically and electronically. I was able to further utilize snowball sampling by having participants distribute my recruitment poster to their colleagues (Creswell, 2007). As stated above, purposive sampling was used; this is the selection of individuals because of their ability to inform an understanding of the central phenomenon of the study. Social workers from a children's hospital were chosen as participants because of their experience working directly with this specific population group. There were four criteria for inclusion in the study: 1) being a social work professional working at a children's hospital; 2) having a Master of Social Work degree; 3) having a minimum of two years of experience in the hospital setting; and 4) having worked with children who were facing death, or who had died, and their families. Of the five participants who responded to the recruitment for the study and were interviewed, only four met all the criteria for inclusion; one participant was excluded after the interview process as she did not meet the criteria of education or minimum experience in the hospital setting. Respondents who met criteria for inclusion were chosen on a first come, first serve basis. A copy of the recruitment letter, *Invitation to Participate*, is included in Appendix A.

3.4 Participants

Although specific demographic information was not collected formally, the participants were invited to locate themselves by sharing what they felt was relevant for this research study (Swigonski & Raheim, 2011). I facilitated this by simply asking participants to tell me about themselves. Further information was gathered through the recruitment process as well as through my observation.

The four participants included in the study were all women ranging between the ages of 30 and 45. The participants' hospital experience varied: the age of the child who had died ranged from newborn to teen, and cause of death was either sudden, unexpected death or long-term illness and complex diagnosis including disabilities. The participants all had a Master of Social Work degree and several years of experience working as a social worker within the healthcare setting. The study was conducted in a large urban centre in Canada where all the participants resided. None of the participants shared being a part of an ethnocultural or racialized minority group or any specific religion.

3.5 Data Gathering

The gathering of data included an in-depth interview and a follow-up telephone call to gather feedback from the participants about the interview process and emerging findings. Three interviews took place in the hospital setting and one interview took place in the participant's home. The participants chose these locations. I gathered the data in individual, one-hour interviews. A semi-structured format, with the use of an interview guide, was chosen to allow for a focused, conversational, two-way communication while still giving both myself and the interviewee the flexibility to probe for details or discuss issues (Maxwell, 2005). I spent approximately 10 minutes providing a description of the purpose and format of the study and

explaining the consent to participate and clarifying that audio would be recorded during the interview. A thorough explanation was provided regarding freedom to withdraw from the process of the study at any point. The interviews were audio recorded and transcribed. Field notes were also taken.

I used a semi structured format for the interviews, to initially allow for the building of rapport as well as for textual information (Creswell, 2007). I began by asking the participants to tell me about themselves. This question was purposely vague to allow the participants to choose how they identified themselves. I then explored the participants' roles within the hospital, moving gradually from the more general role in a hospital setting to specifically their role working with children facing death.

I asked three major questions: 1) Tell me about your experience working with children who are dying; 2) What meaning do you find in your work as a social worker with children who are facing death?; and 3) What meaning do you find with the loss you experience when a child you are working with dies? These open-ended questions afforded participants the opportunity to share their true meaning-making experiences; their answers focused not on the children they worked with but the families, which shifted the entire focus of the study. Consistent with phenomenology, the questions were general and were used to provide a framework for discussion and enhance consistency between interviews rather than direct the type of information gathered (Maxwell, 2005). A copy of the *Initial Interview Guide* can be found in Appendix C.

As directed by phenomenological inquiry, I induced information with questions to explore, clarify, and encourage reflective responses relative to the meaning subjects gave to the experiences they described (Creswell, 1998). I did this to deepen my understanding of the participants' experiences, as well as to reduce the potential for me to make assumptions in an

effort to ultimately enhance the reliability and understanding of the essence of the participants' experiences. As each interview contributed to the development of insight into the topic under study, my scope broadened to encompass experiences identified in previous interviews. This deepened the exploration of identified themes. I used hermeneutic interpretation, which includes introspection on the part of the researcher to examine meaning as it relates to self and then to engage in repetitive and reflection inquiry to gain deeper understanding of the data (Kvale, 1996).

Each interview was transcribed and sent to the respective participant for review. With each participant, I completed a subsequent telephone interview of approximately 30 minutes using a semi-structured format. I asked each participant two questions: 1) Tell me about what the process of being interviewed and reviewing your transcript has been like for you; and 2) Have you discovered any additional meaning or insights into your experience since the first interview? I identified emerging themes and spoke to each participant about these themes to gather their feedback. Several of the participants included additional thoughts or insights. These second interviews were also audio-recorded and transcribed. A copy of the *Follow-up Interview Guide* can be found in Appendix D.

3.6 Data Analysis

The data gathered in the study was transcribed and each participant was given a code to preserve anonymity. Using a phenomenological lens, I analyzed the data by looking for themes, focusing on descriptions of structural and textural statements that described the participants' experience (Creswell, 2007). Structural description is defined by Moustakas (1994) as the context or settings that influence how the participant experienced the phenomenon, whereas textural description is defined as themes that express what the participants experienced. I

included the combined phenomenological process of horizontalization (Moustakas, 1994) and meaning condensation (Kvale, 1996) to draw out the structural and textural essence of the experience of social workers working with families children facing death. Horizontalization refers to the process whereby each statement made by the participant is examined for its relevance to the central research question: What meaning do social workers give to their experience working with families with children facing death? The goal of horizontalization is the development of a coherent story that describes the essence of the structural and textural experience being explored. Meaning condensation is the process of grouping the statements into meaning statements (Kvale, 1996). Its goal is to reduce the data into meaningful themes. Focusing on structural and textural statements allowed emerging themes, or meaning statements, that speak to these particular social workers' experience and the meaning they give their experience to be uncovered. Incorporating both the textural and structural descriptions creates the "essence" of the experience (Creswell, 2007).

As there were four participants in total, no data analysis software was utilized. I created a manual process for the analysis of the data by using the codes that had emerged inductively and applied those codes to all of the data collected. The findings evolved from my immersion in the data, theory, intuitive process and the writing and rewriting of this thesis (Cohen, Kahn & Steeves, 2000).

3.7 Ethical Issues

An ethical issue was that of maintaining the anonymity of the participants. Because the study was completed within one hospital, it would be possible to identify participants from the description of the area they work in, such as oncology. These ethical risks were presented to potential participants to consider in consenting to participation.

This same ethical issue could also be said of the potential risk of identifying families who accessed the hospital for their child who was facing death. The information regarding families with children facing death was carefully shared by participants and I excluded as much identifying information as possible in an effort to protect identities.

4: Findings

This study seeks to gain knowledge of the essence of the social workers' experience in working with families with children facing death. To arrive at these findings, I first immersed myself in the data. Then, using a phenomenological lens, I analyzed the data looking for the essence of the participants' experience through meaning-making statements. After careful review, several themes emerged. In this chapter, I will discuss my findings, which I have broken down to five areas of meaning-making: what brought participants to this work; meaning-making within the function of the role; connection and companionship; challenges faced within the role; and finally, the lessening of suffering. I have broken down each area further using meaning-making statements spoken by the participants, to illustrate the findings through their own words.

4.1 What Brought Participants to This Work

Meaning-making began for these participants in locating themselves. They were professionals who had advanced education and knowledge in the field of social work and expertise in working with a very small population of people: families with children facing death. The essence of their experience began in their journey to this particular role. It is important to note that it is their role as social workers in this specific field that allows these participants access to working with this population and it is their professional experience I am exploring in this study. Two sub-sections emerged from the data: "I am meant to be doing this," and "how I make sense of it."

4.1.1 "I am meant to be doing this." Participants spoke of their role working with families with children facing death as more than their job, they spoke about their role as though it was a part of their identities, a calling even, "For me, it's not just a job, it's my life." A calling, as defined by Hirschi (2012) is "a consuming, meaningful passion for a particular career domain or work that a

person perceives as her or his purpose in life” (p. 480). The participants had chosen a professional role that allowed them to create meaning in their lives and that spoke to the essence of who they are as people, beyond their professional degrees.

Working in this role was not accidental, nor a result of circumstance, but rather something participants actively sought out: “I really wanted to work with children and families, which has always been my area of interest ...” This participant had a desire to work with children and families and worked academically and professionally towards her goal by pursuing a profession in social work and a position in healthcare, working with children and families in the area of pediatric palliative care.

Beyond the specific education and training needed to allow participants access to work with families with children facing death, specifically a Masters of Social Work degree (MSW), participants spoke as though they were uniquely qualified to be doing this work based on who they are as individuals, “I really believe it comes from your values, your beliefs, your upbringing, or even just who you are.” One participant articulated characteristics she valued within herself that she felt complemented her education and brought her to this particular role, demonstrating her feelings of finding her calling, saying “I’m good at my job when it comes to bereavement” and other similar statements discussed throughout these findings.

Participants’ choice of vocation was a large part of the essence of their experience because it is so thoughtfully chosen and tied directly to their identity, to their whole being. Participants did not compartmentalize their job from the rest of their lives, but rather perceived their job as a part of their identity. One participant articulated this by describing her work as a consuming passion; she was “meant to serve families.” In saying she is “meant” to be doing this work, this participant implied she is fulfilling her passion, what she felt is her purpose in life.

4.1.2 “How I make sense of it.” All four participants spoke to their role working with families with children facing death as more than a vocation. As shown above, the participants described their work as their calling. Two participants went even further and shared their personal experience with death and dying as it related to the meaning they made in their professional role of working with families with children facing death.

The first participant shared the personal story of her brother, whom she was very close to and who died. She said, “The reason why I believe I can do this work today is because [my brother] gave me the gift of not being scared of death.” ... “I think it’s important to know this because that is how I make sense of it.” This participant was called to this work from personal life tragedy. From that experience, she had formed a set of beliefs around death and dying and she noted that it is these beliefs, values and strengths that helped her “make sense” of the death and dying she witnessed in her role working with the families of children facing death. She believed she is uniquely qualified for this work and found meaning in taking that “gift” and using it to serve others.

A second participant shared her personal story of what brought her to this role and why she believed she was meant to be doing this work:

When I was [a child, I spent a period of time] in hospital. While I was in hospital, several children passed away so I had the experience of having a friend die quite young and I had that early experience of, ok, life is important.

This participant had experienced loss through death in her past and valued her experience because it illustrated for her at a young age that life is fleeting and not to be squandered. She had taken this experience and found meaning by pursuing a vocation where she serves others who are experiencing great loss as she felt she could empathize with these families and had some

understanding of their hospital experience. This is how she found meaning and this is what called her to the role. It is how she makes sense of it.

4.2 Meaning-Making within the Function of the Role

As discussed above, meaning-making for participants began in the pursuit of the role itself. Participants spoke about being called to the work and tailoring their educational and vocational goals to working with this particular population. They described their role as a part of their identity and described their work as an honour and privilege. Next, I will discuss the essence of the work itself and the meaning-making participants found within the daily function of the role. The sub-categories I use to best demonstrate this theme are: honour and privilege, raw moments of life, bearing witness, and performing.

4.2.1 Honour and privilege. When I asked participants what brought them to this work, each spoke emphatically of their admiration for the families they served, “I see it as a huge honour and privilege to be part of this experience with the family.” At first, I dismissed the numerous declarations of ‘honour and privilege’ spoken by participants. The participants said these words with such repetition that I mistakenly undervalued the meaning they attached to these particular words. Only at the end of my exploration of the findings did I come to realize the significance of these words to the participants speaking them; the participants are not unsupported by real conviction or action but quite the opposite, ‘honour and privilege’ was the essence of their experience.

Privilege is defined as “a right, immunity, or benefit enjoyed only by a person beyond the advantages of most” (“Privilege,” n.d.). Honour is defined as “high respect, as for worth, merit, or rank” (“Honour,” n.d.). The participants have told us a great deal with their choice of words. The participant was honoured, by which she was telling us she felt honoured to be working with

these children and families and had deep respect for the role and the families with whom she worked. She recognized that it is a privilege to be able to work with this population and be a part of each family's story.

In moving forward through these findings, participants described each area of meaning-making as an honour and privilege. I do not reference additional quotes here as they speak to specific findings described further on but I encourage the reader to not repeat my mistake and undervalue these words, as they are powerful and speak to the essence of the experience of each one of the participants of this study. Working with families with children facing death is a unique professional role that, as shown throughout these findings, is as emotionally impactful as it is rewarding.

4.2.2 Raw moments of life. Much of the function of the social work role working with families with children facing death is to be present and support families in the 'raw' moments, the intense emotional experiences had by a family with a child who is facing death. Participants spoke to the impact these moments had on them. One described the experience as a privilege, saying: "It is such a privilege to support families during that time, in that their grief is really raw." Other participants shared the sentiment of the experience: "It is such a privilege to be acquainted with these very raw moments of life." It is clear that these 'raw' moments, these experiences that give unique and special insight, however painful, are considered a privilege; however, the participants felt privilege even to be acquainted with families going through these experiences and be given the opportunity of supporting them.

The privilege or 'gift,' as I describe below, is the emotional intensity of recognizing the fragility of life: "It is a gift to be able to truly live and witness and experience the rich depth of what life is." Participants described finding meaning to live, witness and experience; to share

with and be impacted personally by their role working with families with children facing death. One participant found meaning in living vicariously through her patients who reminded her in these raw moments that “life is precious, every-single-day.” It reminded participants of life’s magnitude: “All of this, this is life.” Within the daily function of their role, participants live, witness and experience life and death with such intensity and frequency that the meaning made impacts their personal outlooks on life.

4.2.3 Bearing witness. The existential encounters with the patients and their families call the participants to bear witness, by which I mean they choose to see and be witness to another person’s vulnerability and they humbly choose to see and be witness to suffering (Arman, 2007). Bearing witness is a prominent theme that emerged throughout this research.

Participants found meaning in being able to meet the needs of the families they served with simply being present: “It is such a unique opportunity to be with people at that time and sit in the silence and sadness with them and yet still be there to support them.” Bearing witness to the grief highlighted for one participant the significance of being present for another person: “I just come and sometimes I would just sit in a room while parents cried and cried and cried. There is nothing I can do; I just need to let them cry.”

Again, participants found meaning in their belief that they were uniquely qualified to do the work and were thus successful in their role. One participant described this conviction, saying: “I think a lot of staff are uncomfortable with that sadness...I think a big skill to have when working with families is to be comfortable sitting with that silence and that sadness.” This sentiment was mirrored by a second participant: “I think it takes a unique person sometimes to be able to do that.”

This participant shared an experience that had stayed with her and highlighted for her the magnitude of the complex nature of her role working with families with children facing death:

When I think of the most devastating death for me in the last three months, it was the death of a baby born at 32 weeks gestation, because of the profound howls of the parents' cries holding their baby; the tears streaming, the shaking, trembling, holding their baby.

This participant continued to speak about her experience and went on to describe the experience as "profound and utterly devastating to be present during such a private, intimate moment."

"Profound and utterly devastating" is a heavy statement demonstrating the essence of this social worker's experience, brought about through her professional role working with families with children facing death. Participants gave of themselves to fulfill their role and meet the needs of the families they worked with, but it was at a personal cost. Meaning-making for this participant could not be contained within her professional role but left an impression that affected her as a human being.

4.2.4 Performing. As discussed above, participants came to this work with a set of beliefs and values that they perceive sets them apart and enables them to do this job well. They find meaning in applying this intrinsic skill set to lessen suffering when working with families with children facing death: "My role is to make it as gentle as possible, that is how I see it, to make it as respectful and dignified as it can be." It was this participant's belief that her role was to be gentle, which she valued because she saw being gentle as showing respect and dignity to the families she worked with.

Participants hold their own beliefs around what families need and find meaning by meeting those needs. As stated at the beginning of this section, one participant clearly stated, "I'm good at my job when it comes to bereavement." Several participants spoke to this effect as

well: “I don’t think it helps families to try and fix it,” “I can listen,” “I can be supportive,” “I don’t come with my own agenda.” Each of these statements held meaning for the participant and validated that they were good at their jobs because in fulfilling the functions of this role, the participants felt they were meeting the needs of the families they served.

Several participants spoke about ‘performing’ to meet the needs of families with children facing death: “This may sound really crass; it is almost like getting ready for a performance.” Participants’ beliefs around the needs of the patient and their families guided these performances: “It is like putting on that mold, which I believe meets the family’s needs in an appropriate manner. That is my belief.” One participant spoke about how important and “sacred” these moments with families were and how the acknowledgement of the moment being sacred motivated her performance: “The images I have of my families who have lost a baby are very sacred. I put them in a very sacred place in my mind because I saw something that no one else should see.”

Another participant described her performance when working with a family suffering the loss of their child:

You are performing a very important role that day, it’s not that I’m not myself, but I am editing myself. I am making myself to be a very compassionate, calm, focused person in that time of grief because I need to be that for the family.

These participants encompassed what they believed the families they serve needed, based on their own beliefs and values, even if that meant editing themselves. It was not about them but rather about meeting the needs of the families they serve.

4.3 Connection and Companionship

Social work has a unique and relevant role in the healthcare system. Working with families with children facing death stands out among other roles in terms of support for the population served and the connections formed with families. It is a “very unique environment where you are surrounded by authentic human relationships, every day,” a powerful experience that participants translated into meaningful connection and authentic relationships with both children and families. In this section, I will discuss my findings about connection and companionship, which break down into three sub-themes: “like a hero”, “heavy responsibility” and “depth of intimacy”.

4.3.1 “Like a hero.” Participants reported feeling valued by the families they work with, which was meaningful for them because it validated their roles and provided them an immediate sense that they were making a positive difference. One participant described it thusly: “You are like a hero. You come into the room and the family is [gasp]. They want you around.” Commenting further on the positive feedback from families, she continued, “It’s amazing! To have that experience, every-single-day.”

In their role working with families with children facing death, participants built strong bonds both with their colleagues in the medical profession and with the families they serve: “The family feels that they are cared for and their relationships are genuine and authentic.”

4.3.2 Heavy responsibility. The other side of this experience is an acknowledgment by the participants that they became a part of the most traumatic experience of that family’s life: “That family will never forget that experience; you will be embedded and tattooed in their mind.” “Embedded and tattooed” is a description that evokes images of permanence. The interaction between professional and patient will travel with the family forward through time.

The families' memories of the professional social worker are tied to the memory of their loved one, their child who experienced a life-altering event or who has died. The acknowledgement of this by the participants demonstrated the weight of responsibility they felt to the families they served: "How difficult, of course, when a child dies."

One participant said, "It will be traumatic." It is unclear whether she was referring to the event being traumatic for the family or for her. The use of the word traumatic elicits strong emotions that suggest the participant was impacted in a holistic way, by which I mean affected on a personal level that reaches her as a human being, and goes much deeper than her role as a professional.

Each participant shared a story of a specific situation that was particularly difficult for them, all describing their experience as "so traumatic." One participant spoke about a family she had known for a long time and having to tell that family that their daughter had relapsed and was going to die:

I was having an anxious reaction internally which is obviously a very selfish way to make sense of that moment, but I think I was tangled up in my grief and my fear and just knowing this family and just knowing how devastating it was going to be, and it was; they were sobbing hysterically, mom started vomiting. It was a total, absolute nightmare. This participant described the experience as a "nightmare" and was able to articulate that this experience was particularly difficult due to her connection with the family and witnessing their grief.

One participant described her continuous exposure to death and dying as an assault: "It is almost like an assault to yourself each time that you think about death and dying." Assault is a very powerful word and calls up an image of being attacked, hurt, and wounded. This participant

described being wounded, “assaulted,” repeatedly in her professional role and touched on the difficult nature of fulfilling this function for families. It is a heavy responsibility with a negative personal impact.

4.3.3 Depth of intimacy. Participants spoke about meaning-making in their relationships with the patients and with others on the multi-disciplinary hospital team. Each participant shared a great deal about the intensity of her daily work life and how that intensity, or, as expressed by the participants, ‘raw moments of life,’ created strong bonds with the patients as well as the other members of the team: “You are sharing moments of intimacy with colleagues to a depth of intimacy that you don’t share with friends and family in your life.” This bond is described by one participant as “strong compassion and companionship. We are like a big family.”

This participant spoke about a dying child whose family did not want to leave her ‘hospital family,’ that is, the social worker and other care providers: “I think that is really hard because the family doesn’t want her to go to [palliative care]; they want her to stay on this ward because this is their family and they want her to die here, [with] this family.” Families felt connected to the social worker who had created a genuine and authentic caring relationship with them, which only bonded more tightly under the intense emotional situation.

This also translated for some participants into a disconnection between work and home life. It was difficult for those outside of this specific role to understand the depth of human emotion experienced by participants on a regular basis: “Our friends and families don’t want to hear about our grief...they can’t relate. They don’t know the frame of reference of what that’s like.” Sharing intense moments created strong bonds between families with children who are facing death and their health care team, in particular the social workers on this journey alongside them as possibly their only available emotional support.

4.4 Challenges within the Role

The role of working with families facing death is held by social workers working in a multidisciplinary medical team within a large healthcare structure. Participants spoke of several challenges they faced and how their work with individuals and families was impacted within the larger context. The sub-themes that emerged are: “this is a life,” “someone to talk to” and “when self-care fails”.

4.4.1 “This is a life.” Several participants spoke about the challenges they faced working within the multidisciplinary team. One participant shared about finding meaning in her role as an advocate for the families she served. To understand her experience, it is important to note that this participant worked in an area of the hospital with a high rate of infant death. She spoke about how the meaning-making she gained from her experiences on this particular hospital ward was in her value of quality of life and looking at the big picture. She respected and honoured families by advocating for them to ensure ethical practice. One particular story stood out for her as illustrative of her experience. She shared:

This baby was born at 23 weeks and the parents wanted to do everything to keep the baby alive. This was the type of child who would most likely end up in a wheelchair and would require 24 hour care. Then the baby’s skin started to slough off. It was horrible. This baby was in so much pain. I said to the doc, “Why are you doing this?” And he said, “Because we can.” At that point, I had to call the ethicist. We had a table about the baby [with all the professionals]. We are keeping infants alive that really Mother Nature said should not be alive and it’s, “Because we can.”

This was a very difficult situation for this participant, one that stayed with her. Her values around life, quality of life, and death, did not meet with those of the doctor. Further, she stood up to

what she felt was unethical and became an advocate for the family and the child facing death: “I think I took it way more to heart; this is a family, this is a human being, this is a life.” To do so, she went against her colleagues and aligned herself with the patient and family, something other participants also describe doing. This participant made meaning by advocating for the family’s long-term best interests, even though that meant opposing the structure in which she worked. Most important for this participant was actively questioning: “When you look at the size of these babies and you look at the aggressive medical interventions and at the same time the survival rates, you start to wonder. Is this the right thing to do?” She made meaning by being a part of the larger existential conversation.

Parents think, “My baby is going to be ok, we live in 2012 and there is every medical intervention, right?” No, your baby may die, your baby may likely die, or your baby may survive and likely have severe disabilities.

Participants make meaning by looking at the big picture and being an advocate for both the families and the children. Having knowledge about long-term outcomes and what that really means for a family is meaningful to them and unique to their role in the healthcare team.

4.4.2 “Someone to talk to.” One of the main themes I found in reference to the negative impacts of the participants’ role is the momentous importance of informal support from colleagues: “To have someone to debrief with and to have someone to talk with.” Having colleagues who had similar core values and with whom they feel a connection was critical to their emotional well-being. One participant shared how difficult her role became when she did not feel like she had that support: “We didn’t get along at all; we had different values, different beliefs, different ways of practice and it made it really, really hard.” This participant described how inseparable her role was from her identity and the negative impact she encountered when

working with someone who did not share her same values and beliefs. The lack of connection with her colleague led this participant to feel isolated in her role and without the necessary support to process her experience: “I didn’t have good support working there so I think I internalized a lot of it. I had to leave eventually because I didn’t have the support.”

Informal emotional support was a key factor in job satisfaction and emotional well-being of participants. Further, the importance of formal processes that acknowledged the emotional needs of staff was identified as key in the meaning-making process for participants. One participant spoke about the formal processes in place on her ward:

I know what I loved about the [ward] was the support they provided to each other.

Immediately following a child’s death, during the next clinical rounds, they would light a candle and each staff person would share something that was on their mind about the family or the child who had passed away. It was very much an emotional debriefing.

Then it wasn’t until three months later, they would book another time where they would do a clinical debriefing where they would actually talk about what went well, what didn’t, what can we learn from this, how can we move forward? I thought it was really amazing that they separated that out and met that emotional immediate need first but still did the clinical work of how do we continue to improve and change and move forward in our practice.

Having formal processes in place was crucial to allow participants emotional space for their own health and that of other staff. The participants spoke about a gap in terms of formal in-house supports around grief and loss: “I am quite close with a number of staff so feel comfortable going to them” ... [but unfortunately] ... “I think that is something that is missing more in the acute care. My experience here is that there is not a lot of support, formally.”

4.4.3 “When self-care fails.” Participants shared that their role is difficult and emotionally taxing. The role is learned on the job and if formal supports were not in place participants were not able to maintain self-care and would ultimately experience burn-out, as they had emotional as well as professional needs that went unmet: “We don’t get a lot of education or preparation or support as to how do you do that.”

One participant spoke in particular about the concept of self-care and how that is reflected in the daily role of working with families with children facing death: “I think we talk a lot in social work school about self-care but what does that really look like practically. Yes, do self-care but when self-care fails, how do you recognize that and when do you make a change?” She continued by speaking about the real issue of burn-out of individuals who work so closely in this professional role: “For me, I realized that I was burnt-out. I had stopped entering into family stories and had become very objective and removed and I knew that was the point that I needed to leave.” The lack of essential supports for participants led to the weight of the role adversely affecting them to such a degree that they were not able to find meaning in the role and often ‘burn out’ and leave the role.

4.5 To Lessen Suffering

Participants considered their work a calling and reported finding meaning in the role through meeting the needs of the families with children facing death. An overarching theme that emerged is that of lessening suffering.

Participants describe giving of themselves to meet the needs of the families they work with, often at great emotional cost. Within the role of working with families with children facing death, participants experience grief and loss. One participant shared: “It’s a heavy responsibility, witnessing dying.” This statement highlights the magnitude of the post these social workers hold.

One participant shared that the most difficult time for her is when she feels she has not met the needs of the family, which, ultimately, is to reduce their suffering: “What makes it harder is to see another human in such pain and wanting to take the pain away. I don’t think there is anything worse.”

The participants described that they continue to do this work because they feel they are providing something to families that they themselves believe to be important and valuable. The most tangible, measureable result for participants is to see families they work with find comfort in their interaction; to lessen suffering. The participant continued by sharing: “I feel I was giving something going through these deaths with the families.”

4.6 Conclusion

Identifying the essence of the meaning made by participants of this study, and examining the meaning social workers give to their experience working with families with children facing death, can best be broken down using the four identified themes: what brought participants to this work; meaning-making within the function of the role; connection and companionship; and challenges faced within the role. The participants find meaning by lessening suffering for families facing the death of a child.

5. Discussion

In this chapter, I will discuss the main findings of this study. I begin by introducing my research question and go on to summarize my main findings. Next, I will link the findings to the existing literature and discuss the credibility and trustworthiness of this study. Finally, I will present support for my standpoint that research in this area of study is valuable and should continue in view of its positive implications for improved policy and practice.

5.1 Summary of Significant Themes

This study sought to explore the meaning social workers give to their professional role working with families with children who are facing death. Using a phenomenological lens, I analyzed the data by looking for themes, focusing on descriptions of structural and textural statements that described the participants' experience. The overarching theme that emerged is participants find meaning in their professional role by utilizing their unique gifts, their calling, and by helping others. The participants found meaning in giving of themselves to lessen the suffering of others. Participants believed that they had a distinctive gift in their ability to be available to families and meet the needs of those families with the goal of lessening suffering, despite the cost to self. By giving of themselves for others, they were able to express who they are; their beliefs and values translated into their profession and they were able to make a significant difference in the experience of families with children facing death.

As discussed throughout the findings of this study, participants described being 'called to' this work and being uniquely qualified based on who they are as human beings, in addition to their education and experience. They measure their success by their ability to lessen suffering for the population they serve. When successful, they are validated and feel positive about their work, which reflects back and validates them as professionals. If they are not successful, the impact on

the participants is far-reaching, causing them to question their ability both in their role and outside of it in the greater context of their lives. This existential cycle is at the heart of the participants' meaning-making in their professional role working with families with children facing death.

5.1.1 To lessen suffering. After much time spent studying the findings, what became clear to me is that they have several significant themes, including performing, bearing witness and connection and companionship, as discussed below. What I realized is that each of these themes reflects a greater meaning-making for the participants, and that is to lessen suffering. The most significant theme in this study is that the basis of meaning-making for participants is tied to their ability to alleviate suffering for the children and families with whom they work. As previously stated in the literature review, the illness and death of a child is one of the most difficult tragedies a family will ever have to face. What happens between a family and their healthcare team is vitally important in determining how the family experiences this loss (Browning, 2008). What is missing from the literature is the experience of the healthcare team, notably for this study, the social worker. To find meaning in their role, it was critical for participants to feel effective in their pursuit of ways to alleviate suffering for the families they serve.

One participant said that there is nothing worse than seeing another human being in such pain and not being able to take that pain away. In an effort to meet that need, participants engaged in a number of actions that ultimately fulfilled their purpose by lessening suffering for the children and families they work with, and in turn creating meaning for themselves within their role. It is worth noting that the participants may not be aware or able to articulate that their actions are tied to the meaning they make in lessening suffering.

5.1.2 Performing. A good illustration of the actions engaged in by participants that lead to the greater goal of lessening suffering is described in the findings as ‘performing.’ One participant shared her belief that her role was making the experience of families with children facing death as gentle and respectful as possible. To meet this need of families, this participant edits herself and presents for families as a compassionate, calm and focused person. In meeting the participant’s perceived needs of the family, she created meaning in that she feels effective in her role and is able to lessen suffering for the family.

In my review of the literature, I did not find articles that spoke to this particular aspect of social work practice. I acknowledge that my review of the literature was not exhaustive and there may be more information outside of works specifically dealing with social work that speaks to individuals ‘performing’ to meet the needs of the population they serve. As the literature regarding the experience of social work in pediatric-end-of-life is limited, this may be a unique perspective.

5.1.3 Bearing witness. Another action engaged in by participants was to bear witness. Bearing witness is a large sub-theme within the findings of this study. All four participants touched on this theme in their description of the essence of their meaning-making within their role.

To bear witness is described by one participant as “profound and utterly devastating.” To witness and be present for the most intimate moments of a family’s life is a heavy responsibility. Participants prided themselves on this, and felt they had an intrinsic skill to be able to sit in sadness and be present for families; the participants valued being able to lessen suffering with simply their presence.

Bearing witness is at the core of the participants' beliefs and values and may be the most practical action they take to lessen suffering. One participant described bearing witness, being able to be sit with silence and sadness, as an important skill. Because it allows them to see the positive effects of their intervention immediately, bearing witness was essential to participants' meaning-making. One participant shared that she was proud of her ability to fulfil this role for families. The immediate positive impact translated to a sense of accomplishment for participants that reinforced for them the importance of their role to the families they served. Because of the immediate positive reinforcement, the participants also felt as though they were successful in their endeavors to lessen suffering, which validated their professional role as well as their core beliefs and value as individuals.

Participants also described bearing witness as a gift to families that was given at personal expense. Participants described witnessing the death of a child and the suffering of the child's family as 'traumatic' and the most difficult aspect of their role, yet they continued to bear witness because they saw it as a gift to families and found meaning in the value it held for them. Arman (2007) speaks to the weight and responsibility of bearing witness and the giving of oneself to being truly present and connected to another person's suffering. This is further supported in the findings by the participants who named the experience a 'heavy burden' but continued to carry that burden.

5.1.4 Connection and companionship. The largest impacting factor for the participants, in their responses to the death of a child, is the connection with the family. This is to say that participants have a more difficult time emotionally enduring the suffering of families with whom they shared a close bond. One participant described having to tell a family that their child had relapsed and would likely die. This participant said that the most difficult aspects of the

interaction with the family was knowing the family well, sharing a bond through their professional relationship, and anticipating the grief the family would experience with this news. The participant's anxieties were reinforced when the family began to react to the news by breaking down and wailing and vomiting with grief. All participants recounted that witnessing the intense suffering of a family and not being able to alleviate the suffering was the most difficult aspect of their role working with families with children facing death.

5.1.5 Heavy responsibility. I think it is important to acknowledge in this discussion chapter the significant weight of this role on participants. Participants affirmed that they were 'called to' this work and that they are 'meant' to serve families. They spoke about the positive aspects of feeling honoured and privileged to be able to do this type of work and be fulfilled knowing that they are having a positive impact on families at a most difficult time. The participants stated they felt they were giving families a gift by going through these deaths with them, but it does come at a cost.

The descriptors used by participants include "embedded and tattooed," "traumatic," and an absolute "nightmare." One participant said, "It's almost an assault to yourself each time you think about death and dying." This is a very graphic and evocative way to describe one's workplace. These descriptors also reveal thoughts of dark intensity that are not easily left at the door at the end of the day. This role is as emotionally consuming for these participants as it is rewarding. Without proper supports, the emotional impact of the work could easily overwhelm the meaning made by participants in working with families with children facing death.

There is a large amount of research done on the effects of stress on personnel in the caring profession as well as research on specific issues around burn-out and other negative outcomes for individuals working in high impact environments. As discussed in the implications

section below, this is an area identified in this study that needs to be addressed further in policy and practice.

5.2 Findings in Relationship to the Existing Literature

I found that there is very little known in regards to working with palliative pediatric patients and even less about social workers and their experiences working with this population. The small body of research completed in the area of social work and palliative end-of-life care is focused largely on the function of the role of the social worker in relationship to psychosocial needs of the family (Kramer et al., 2003).

This is an important distinction because, although the function of the role is a theme that emerged in the findings of this study, this study speaks only to how the function of the role creates meaning-making for the participating social workers and how their day-to-day functions lend to the essence of their experiences. For instance, Jones (2006b) described the key functions she found within the social work role in pediatric end-of-life care to be inclusive of:

“counselor/companion/guide, advocate/communicator/coordinator of services, resource broker, interdisciplinary team member, and ethical consultant” (p. 42). The themes found in this study support Jones’s findings in regards to the key functions of the role: counselor/companion/guide is mirrored in these findings, as are advocate, interdisciplinary team member, and ethical consultant. What distinguishes this study from Jones’s study is that the findings lend themselves to the experience of the social worker instead of the patient and family.

The role of meeting the patient’s and the family’s identified needs is a key theme throughout the literature regarding the role of the social worker in end-of-life care (Hodgson et al., 2004). Similarly, the participants of this study found meaning in their interaction with the children and families they serve, specifically when they felt able to lessen suffering for these

families and meet all evolving needs as they arise. Thus, the similarities between this study's findings and Jones's findings are significant. It would be reasonable to conclude that the current body of literature's findings on the psychosocial needs of children and their families in pediatric end-of-life care will mirror the themes of this study's findings.

Using Jones's (2006) findings as a guide, I will touch on the similar themes of this study's findings and speak to the functions of the roles that are found to make meaning for participants: companion, advocate, interdisciplinary team member, and ethical consultant.

The role of counselor/companion/guide is found in this study in broad strokes. Participants found meaning in being present with families in the ordeal of having their child facing death. This companionship often looked like bearing witness, which is discussed in detail above. When working with families, the role of counselor and guide comes to the fore in learning diagnosis, decision-making and planning, supporting the family to make informed decisions, and guiding the family through the large healthcare system. What separates this study from that of Jones and other studies currently looking at the palliative end-of-life care is that the focus is on the essence of the role of the social worker and her/his connection with the family as opposed to the individual tasks; it is a larger holistic examination of the relationship between larger system, social worker and family.

The roles of advocate and ethical consultant are listed in Jones's (2006) study as key functions for social workers in pediatric end-of-life care. This theme is also found in my research, but the two topics are described together as a joint issue and only in context to one another. One participant shared her experience with advocating for the 'big picture' for families. She pointed out that the family will often ask for the most aggressive interventions and she felt it is her role to inform the family of all of the options and outcomes for their child. This is

supported in the literature by Carter et al. (2004), who speak about the importance of the social work role in advocating for the patient's voice to be heard, but also in ensuring that the families have all the information they need to make a decision that makes the most sense for them as a family.

This participant spoke passionately about her belief that in order to engage in ethical practice, the interdisciplinary team must look at the big picture and support the family such that they have all the information necessary to ensure they are making the best decision for the patient and for themselves. She revealed that, in her experience, it is often up to the social worker to engage in these conversations with the healthcare team and oppose the course of action, if necessary. The role of the social worker as advocate for ethical practice is supported in the literature by Peck and Norman (1999), who described social workers as more likely than any other healthcare professionals to challenge the status quo in their practice. Given that social work has a strong foundation of advocacy and ethical practice, it is yet another responsibility that often falls to the social workers in a multi-disciplinary team and one that is shown to be meaningful to this study's participants.

Lastly, participants of my study discussed the role of 'interdisciplinary team member' in several aspects of meaning-making. One participant spoke about her experience of feeling like her interdisciplinary team was a second family and sharing this strong familial bond with her team due to the emotional intensity of the work. Another participant spoke about finding meaning as a member of the interdisciplinary team and feeling supported by an informal process that allowed for debriefing and processing to occur naturally. In contrast, another participant described a negative experience she had working with someone who did not have similar beliefs or goals and how that affected her to such an great extent that it led to her leaving her position

due to what she described as burn-out. Each of these experiences supports the finding that working as part of an interdisciplinary team creates meaning and was thus integral to the essence of the participants' experience.

What differs between my findings and those of Jones (2006b) is the focus on practical aspects of the role in terms of associated roles, such as resource broker. None of the participants in my study spoke about practical tasks associated with their work. I surmise from the absence of that information that the participants in my study did not find meaning in performing those tasks for families in the same way that they experienced meaning in providing the emotional support and intensive family work. This difference may arise from the origins of the two studies. Jones's research and most other research on this subject was, or is being, performed outside of Canada, where the medical system is dramatically different.

It would be remiss of me not to include Jones's (2006c) study, in which a poem was used to present the data because of poetry being the best vehicle for expression of complex emotional experiences. Themes that were represented in the poem included social workers' feelings of being 'honored' and 'blessed' to work with this population: "I have been given/a gift/It is the children I have known...I feel honored and blessed/ To have helped" (1-3, 12-13); an emphasis on easing pain: "hopefully/to ease their pain/in the process" (15-17); and to be present for children and families: "I am able to be there/for the kids/and families" (34-36). Looking at the experience of the social workers themselves is valuable and gives insight directly related to my research question: What meaning do social workers give to their experience?

Of the available literature, Dr. Jones's research most closely resembles my own and thus reinforces my findings. This is significant as it demonstrates similar areas of meaning-making for social workers in pediatric end-of-life care in different geographic and cultural settings.

5.3 Credibility and Trustworthiness

Why we should take the findings of this research seriously? The criteria for evaluating quality in qualitative research are credibility and trustworthiness. Credibility refers to the participant's views and the researcher's interpretation and representation of those views (Polit & Beck, 2012). A researcher's transparency in descriptions of his or her experience conducting the study and competence in verifying the research findings with participants is proportionate to the credibility of the study. A qualitative study is considered credible if individuals who share the same experience recognize the findings (Sandelowski, 2000).

I enhanced the credibility of this research study by describing my methods and experience as a researcher when conducting the first one-hour semi-structured interview and then going back to participants for a second short interview to verify with them the themes that were emerging. Also lending to the credibility of the study is that the findings are often reflective of past research done in similar areas, as shown below in this chapter.

Trustworthiness in qualitative research is developed through credibility, dependability, confirmability, transferability and authenticity (Morrow, 2005). Credibility is discussed above. A study is deemed dependable if the study findings were relocated with similar participants in similar conditions (Morrow, 2005). Confirmability refers to the researcher's ability to demonstrate that the data represents the participants' responses and not the researcher's biases or viewpoints. In qualitative research this can be exhibited by providing rich quotes from the participants that depict emerging themes (Polit & Beck, 2012). Just as it sounds, transferability refers to findings that can be applied to other settings or groups. Finally, authenticity refers to the ability and extent to which the researcher expresses the feelings and emotions of the participants in a representative manner.

The trustworthiness of this study was made stronger by adding to its credibility as well as by using numerous rich quotes from participants, and again completing a second interview with participants to ensure that their feelings and emotions were a true representation. As discussed below, the findings of this study are reflective of similar research, which also demonstrates trustworthiness in its transferability.

5.4 Implications for Policy and Practice

The most obvious implication for policy and practice that this study revealed is the need for formal processes to support social workers in managing the complex emotional aspects of their role. All of the participants spoke to their strong belief that formal processes are of benefit to professionals working in pediatric end-of-life care, and particularly so for social workers working with families with children who are facing death. Only one of the four participants has worked in a healthcare facility that had formal processes for debriefing and processing the emotional impact of her role. All four participants identified the need to have such processes in place to manage the emotional needs they have in direct relation to the work they do with families. The absence of such processes is a gap in practice that needs to be addressed.

The absence of these formal processes is a key theme in my findings. Nyatanga (2015) lists strategies to avoid burn-out, including: regular support, debriefs, supervision and, if needed, time away from the stressor. Pattison (2011) emphasizes that the amount of emotional support needed by staff cannot be underestimated. Support is often provided through clinical supervision and staff counselling. Although most of the research on palliative care burn-out pertains to nursing staff, it is applicable to social workers as arguably the professionals who spend the most intimate time with the family. Baumrucker (2002) speaks to the high rate of burn-out in palliative and oncology care with adults. He found that burn-out was significantly more common in those

who felt they were insufficiently trained. This has direct implications for the participants in this study, even more so as the population they work with is children, with the added complexity of supporting the parents as well.

This study demonstrates that there is value to be obtained by studying this particular group of people with their specific experience and knowledge, and that further exploration can have positive ramifications for practice in the near future. With the growing interest in pediatric palliative care, more research is needed that studies the professionals who work most closely with children at end-of-life, and their families.

5.5 Conclusion

The purpose of this study was to gain knowledge about the essence of the social worker's experience working with families with children facing death by exploring the meaning these professionals make in this unique role. I first introduced myself and related what brought me to this research. I reviewed the literature to determine what was already known regarding my area of interest. I then outlined my research design, presented my theoretical framework set in generic qualitative approach, drawing on phenomenology and data analysis, and concluded with noting limitations of the study. My findings outline the key themes as: what brought participants to this work, meaning-making within the function of the role, connection and companionship, and challenges faced within the role. In the discussion chapter of this study, I argue that the essence of the participants' meaning-making is their desire to lessen suffering for families with children who are facing death. When they were able to do this, the participants felt that the personal values and beliefs that brought them to this role are validated existentially, a factor that is vital to these professionals, who consider their work more of a calling than a career choice. The results of this study add to the relatively small knowledge base of research in the area of pediatric end-

of-life care and even smaller knowledge base of the experience of social workers in pediatric end-of-life care. Working with families with children facing death is a complex and emotionally intense professional role that participants value as part of their identity. Having knowledge of this phenomenon as experienced by several individuals is valuable and has positive implications for future research and practice.

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Appendices Appendix A – Recruitment Poster

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work

2080 West Mall

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Tel: (604) 822-2255 Fax: (604) 822-

Invitation to Participate in a Study of:
Social Workers Experiences of Working with Children Facing Death

Research Team:

Principal Investigators

Elizabeth Jones, Instructor

Lise Beauchesne, Professional Practice
 Leader, Social Work, C&W

Co-Investigators

Lisa Wilkey, Graduate Student, UBC

Brian O'Neill, Associate Professor, UBC

What is the Purpose of the study?

- To explore experiences of social workers who work with children who are facing death.
- To provide useful knowledge that may have implications for research, professional education and service delivery.

This is a student research project to meet requirement for my Master's of Social Work degree.

What's involved?

- 2 individual interviews of approximately 1 hour each in a location of your choosing and at a time convenient for you
- An opportunity to talk about your experiences and perceptions related to your professional role as a social worker and your work with children facing death.

Who's Invited?

- C&W Health Centre social workers who work with children who are dying or have died.

Appendix B – Consent Form

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work

2080 West Mall

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Tel: (604) 822-2255

Date:

Consent Form

The Experience of Social Workers Working with Children Facing Death

Research Team:

Principal Investigators

Elizabeth Jones, Instructor, UBC

Lise Beauchesne, Professional Practice
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- To explore experiences of social workers who work with children who are facing death.
- To provide useful knowledge that may have implications for research, professional education and service delivery.

This is a student research project to meet requirements for my Master's of Social Work degree.

Study Procedures

Participation in the study will include an approximate time commitment of 4 hours and involve:

- 2 individual interviews of approximately 1 hour each
- Research Question:
What meaning do social workers give to their experience working with children who are facing death?
- You may decline to answer any questions
- The interview will be audio recorded and transcribed by a typist
- You will receive a copy of the transcript of your interview and have an opportunity to change it if you wish, which could take about half an hour
- Receipt of a draft of the report and an opportunity to comment on it which also could take about half an hour
- Notes regarding your comments will be written

No reimbursement will be provided to the participants.

Potential Risks

It is not expected that there will be any risk to those interviewed. However, a list of supportive resources will be provided to all participants in case they feel the need for follow-up support to deal with issues that arose during the interview

Potential Benefits

The knowledge gained in this study may help to understand your unique experience in this field. In order to receive a copy of the findings of the study, please provide your address below.

Confidentiality

A unique subject number with no identifying information will be defined for each participant and used in identifying data files and throughout transcripts.

Computerized files will be stored on a password protected computer. Likewise, during the study, audio recordings and hard copy transcripts will be stored in a locked file cabinet by the student co-investigator at her home.

Study team members and transcribers hired to transcribe data will have access to the data. They will be advised of their responsibilities concerning privacy and confidentiality.

Data will be stored for 5 years in a locked file cabinet at the UBC School of Social Work. After that, tapes will be demagnetized, paper copied shredded and any computer files deleted.

Data gathered in this study will be used for a project in my MSW research course as well as in my thesis. The information may be further used to produce an article for publication. No persons other than those already identified above will have access to the data.

A report of the findings will be made available to participants who indicate that wish and provide an address.

Contact for information about the rights of research subjects:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

Toll free number of the Research Subject Information Line (1-877-822-8598).

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy.

Your signature indicates that you consent to participate in this study.

Consenting to this study includes participating in 2 - 1 hour interviews, participating in review of the transcriptions and giving feedback for a total time commitment of approximately 4 hours.

Your signature below indicates that you have received a copy of this consent form for your own records.

Subject Signature

Date

Printed name of subject

Date

Appendix C – Initial Interview Guide

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work

2080 West Mall

Vancouver, B.C. Canada V6T 1Z2

Tel: (604) 822-2255

Initial Interview Guide

The Experience of Social Workers Working with Children Facing Death

Questions asked during initial interview:

- 1) Tell me about your experience working with children who are dying;
- 2) What meaning do you find in your work as a social worker with children who are facing death?
- 3) What meaning do you find with the loss you experience when a child you are working with dies?

Appendix D – Follow-up Interview Guide

THE UNIVERSITY OF BRITISH COLUMBIA

School of Social Work

2080 West Mall

Vancouver, B.C. Canada V6T 1Z2

Tel: (604) 822-2255

Follow-up Interview Guide

The Experience of Social Workers Working with Children Facing Death

Questions asked during follow-up interview with participants:

- 1) Tell me about what the process of being interviewed and reviewing your transcript has been like for you.
- 2) Have you discovered any additional meaning or insights into your experience since the first interview?