LIFE LESSONS FROM DEATH WORK: A PHENOMENOLOGICAL STUDY OF CHILD BEREAVEMENT PROFESSIONALS IN THE UNITED KINGDOM

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The Supervisory Committee certifies that this ***disquisition*** complies with North Dakota State University's regulations and meets the accepted standards for the degree of

DOCTOR OF PHILOSOPHY

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ABSTRACT

Phenomenological inquiry was utilized to explore the feelings, experiences, and education of bereavement support professionals working in children's hospices in the United Kingdom (U.K.). A total of 15 participants from six children's hospices across the 33 boroughs of London, England, United Kingdom took part in the study. Participants were recruited through a convenience and snowball sampling process and met the following inclusion criteria: (a) currently employed at a children's hospice in the U.K., (b) had a background in mental health, counseling, psychology, or a related field, and (c) their role involved providing support and/or enhanced emotional well-being for children, young people, and families. Semi-structured, individual interviews were conducted to answer the research question.

The research question guiding the study was: What are the experiences and perceived levels of preparedness of bereavement professionals' working with bereaved children, families, and young people? Moustaka's (1994) modification of the Stevick-Colaizzi-Keen method was utilized for data analysis. This researcher identified six themes and various subthemes. The main themes included: the foundation of hospice is holistic, bereavement work entails a unique developmental process, the nature of the work requires additional support and supervision, perceptions of death and disabilities matter, death work allows for a greater focus on life, and children present with unique perceptions and needs related to grief and bereavement. The findings illuminate considerations for grief, bereavement, and death work including education, supervision, and clinical practice. Limitations, recommendations for future research, and implications for counselors and counselor educators are addressed.

Keywords: grief, bereavement, phenomenology, qualitative, counselor education, death education, pediatric palliative care

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DEDICATION

For my grandmother and best friend—Shirley Kuha James. Thank you for always reminding me to stay silly, courageous, and driven. You are greatly missed.

And, to all of those who don’t yet know the greatness they have within themselves.

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CHAPTER ONE: INTRODUCTION

> *…it is my hope that by grasping, really grasping, our human condition—our finiteness, our brief time in the light—we will come not only to savor the preciousness of each moment and the pleasure of sheer being but to increase our compassion for ourselves and for all other human beings.* (Yalom, 2008, p. 277)

Existential theory posits that there are four givens of the human condition: the inevitability of death, isolation, meaninglessness, and freedom (Eliason et al., 2010; Georganda, 2016; Grădinaru, 2017). The inevitability of death could be considered one of the most common threads to humanity; however, perhaps one of the most difficult to explore. As Yalom (2008) suggests, looking at one's mortality could be comparable to 'staring at the sun'; an experience that he considers necessary, but one an individual can only engage in for so long. This core aspect of the human condition recognizes that death is inevitable not only for oneself, but also for one's loved ones and other connections in life (Seligman & Reichenberg, 2014).

According to the World Health Organization (2019), 55.4 million deaths occurred worldwide in 2019. That number has now dramatically increased in 2020 due to a worldwide pandemic of the novel coronavirus (Lee & Neimeyer, 2020). The virus has impacted grief at individual, community, and global levels due to unexpected and unprecedented death rates (Wallace et al., 2020). Additionally, grief researchers have noted more acute grief responses from individuals who experienced the death of a loved one during this pandemic (Eisma & Tamminga, 2020). Thus, the significance of death work is explored due to the prevalence of loss and implications of grief on mental health.

Although death is an inevitable part of life, losing a loved one can have psychological and physical implications (Dunphy & Schniering, 2009; Wilson et al., 2017) particularly due to the type of loss, and the relationship with the bereaved. These implications are particularly significant for children and youth. The risks for bereaved youth are amplified and can include academic, psychological, and relational concerns (Ayyash-Abdo, 2001; Burns et al., 2020). Unfortunately, in the United States, it is estimated that 1 in 14 children will be bereaved of a parent by their 18th birthday (Judi's House, 2020). Although the death of a loved one can be traumatic for any individual, the death of a child is considered perhaps one of the most traumatic (Morgan, 2009). As such, mental health professionals need to be prepared to work with all aspects of grief and loss (Doughty et al., 2011). The prevalence of loss and implications of grief on mental health supports the need for mental health educators, students, and providers to explore the significance of death. Chapter one provides an outline of this researcher's qualitative investigation into child bereavement work. The following areas will be outlined in chapter one: statement of the problem, purpose of the study, research question(s), need, significance of the study, definition of terms, and overview of chapters.

Statement of the Problem

Death, grief, and loss are inevitabilities of the human experience (Doughty Horn et al., 2013; Dunphy & Schniering, 2009; Hill et al., 2018; Wilson et al., 2017). Therefore, most professional counselors will encounter clients who are in a state of bereavement or are facing issues related to death and dying at some point in their careers (Breen, 2011; Harrawood et al., 2011; McClatchey & King, 2015). As grief is a common experience, mental health professionals will ultimately bear witness to clients struggling with issues related to grief and loss (Cacciatore et al., 2015; Dunphy & Schniering, 2009; Harrawood et al., 2011; McClatchey & King, 2015; Morgan, 2009). Yet, in the literature, beginning counselors often reported feeling uncomfortable discussing topics related to grief compared to other presenting problems (Doughty Horn et al., 2013; Kirchberg et al., 1998), while clinicians also reported a lack of knowledge with clients facing loss (Black, 2007; Kramer et al., 2003; Stewart et al., 2000). Nonetheless, grief is not considered a requirement in counseling curriculum (Harrawood et al., 2011; Ober et al., 2012). Additionally, although research on the topics of grief and bereavement are prevalent, therapists' loss experiences, both personally and professionally, are underexplored (Kouriatis & Brown, 2014). Therefore, studying the experiences of individuals working with the bereaved may bring insight to implications for professional practice.

Death crosses cultural boundaries among various groups (Pentaris, 2011; Rolls & Payne, 2004). Thus, perspectives of grief and loss are considered global in nature affecting each individuals' perceptions of death differently (Doughty & Hoskins, 2011). More specifically, the way individuals perceive death relies largely on cultural considerations due to varying beliefs and customs (Pentaris, 2011). According to Doughty and Hoskins (2011), although death is universal, "the experience and expression of grief is individual, with both intrapersonal and interpersonal influences" (p. 25). Thus, education on death, grief, and loss should be considered from an international perspective when training counselors and counselor educators.

Consequently, topics of bereavement are underrepresented in counselor education training and supervision, and most professionals feel unprepared to work with these populations due to a lack of death education (Doughty & Hoskins, 2011; Doughty Horn et al., 2013; Hill et al., 2018; Ober et al., 2012). Furthermore, when death education is available, there is a greater focus on individuals at later stages of life than children (Bagatell et al., 2002). However, the United Kingdom (U.K.) has made child bereavement work a focus through its dedicated training programs, research, and children's hospice facilities (Mash & Lloyd-Williams, 2006; Rolls & Payne, 2004; 2007). Yet, in the United States, issues related to grief and loss for youth are often overlooked and under-resourced (Burns et al., 2020). The United Kingdom currently has more than 50 children's hospices (*About Us*, n.d.-a; *Childrens Respite & Hospice Homes*, n.d.; House, n.d.), while the United States has only three in completed development (*About Us*, n.d.-a; *Childrens Respite & Hospice Homes*, n.d.). The vast differences in number of children's hospices in the United Kingdom vs. the United States led this researcher to the proposed study.

Purpose of the Study

"Purpose is the controlling force in research" (Patton, 2015, p. 248). Therefore, the purpose of this study is to explore the feelings, experiences, and education of bereavement support professionals working in children's hospices in the United Kingdom. Utilizing a phenomenological-qualitative design, this researcher sought to gain a better understanding of bereavement work through the experiences of individuals who work directly with issues of death and dying in children's hospices. Due to the number of children's hospices in the United Kingdom compared to the United States (*About Us*, n.d.-a), the lived experiences of child bereavement professionals in the United Kingdom will be explored.

Research Question

The purpose of a qualitative research question(s) is to explore various perspectives and experiences (Hays & Singh, 2012). This study aims to explore the lived experiences of individuals working specifically in children's hospices. The research question for this study is as follows:

> "What are the experiences and perceived levels of preparedness of bereavement professionals' working with bereaved children, families, and young people?"

Need for the Study

Although perhaps anecdotal, topics of death in the United States (U.S.) are not openly discussed. While death work is a part of local and community hospices in the U.S., there are distinct differences between those entities and dedicated children's hospice facilities. According to Dangel (2002), pediatric palliative care programming provides support for children, youth, and their families who are living with life-limiting conditions. This service allows for holistic care including respite services, death, and bereavement support. Price et al. (2013) reported that the United Kingdom is considered a pioneer in children's hospice care around the globe. As noted previously, the United States has only three children's hospices in completed development (*About Us*, n.d.-a; *Childrens Respite & Hospice Homes*, n.d.) while the United Kingdom has more than 50 (*About Us*, n.d.-a; *Childrens Respite & Hospice Homes*, n.d.; House, n.d.). Therefore, information on the lived experiences of bereavement workers in the U.K. may allow for continued insight into the needs of professionals working with this unique population.

Although the prevalence of death and its impact are known, there is a lack of awareness on the impact of therapists who care for the bereaved (Dunphy & Schniering, 2009). Counselors working with children at end-of-life, including bereaved individuals, are bearing witness to some of the most critical moments in a person's life including intense moments of pain, suffering, and sorrow. According to Hayes et al. (2007), the literature suggested that therapists' overall well-being has an impact on quality of therapy. Therefore, understanding the impact of death and bereavement, especially as it relates to children, should be of importance for mental health professionals (Ayyash-Abdo, 2001; Ener & Ray, 2018); not only for professional practice, but to cope with their own loss experiences (Chan & Tin, 2012).

Counseling literature suggested that training on death was crucial not only for grief counselors, but counselors in all specialty areas (Harrawood et al., 2011; Servaty-Seib & Parikh, 2014). To this point, beginning counselors reported that in practice, discussing topics related to grief and loss made them uncomfortable compared to other presenting problems (Doughty Horn et al., 2013; Kirchberg et al., 1998; Ober et al., 2012). Therefore, counselors need information regarding theory, skills, and interventions to feel competent; however, grief counseling is not identified as a requirement in core counseling curriculum (Doughty Horn et al., 2013; Ober et al., 2012). Gaining knowledge in this area of bereavement may help to reduce stress, compassion fatigue, burnout, and secondary trauma for professionals (Chan & Tin, 2012).

Thus, through this study, the researcher sought to gain a better understanding of bereavement work through the perceptions and experiences of individuals who work in children's hospices. Due to a lack of consistent bereavement education, inclusion of internationally relevant death education and national/international professional organizations for bereavement training is needed (Doughty & Hoskins, 2011). The literature identified a gap in the understanding of death work, education, and therapists' experiences, especially as it related to international work. Therefore, this researcher designed the study to address this gap through exploring the lived experiences of bereavement workers at children's hospices in the United Kingdom.

Significance of the Study

According to Kouriatis and Brown (2014), grief and bereavement research is widely explored, yet, "therapists' experiences of loss seems to be relatively unexplored" (p. 89). Therefore, this study will contribute to the literature by exploring the experiences of mental health professionals working directly in children's hospices. Significant literature is currently available on implications for the medical field (predominantly nursing) on end-of-life work; therefore, this study will look to address a gap in bereavement literature focusing on mental health professionals' experiences with children and families. Information will be provided on the experiences of those working to support children, youth, and their families dealing with life-limiting conditions, death, and bereavement in children's hospices. A particular focus will be on levels of preparation in order to shed light on potential education and training needs for mental health professionals working in the areas of death, dying, and bereavement. Results may provide insight regarding implications for counselor educators, practicing counselors, and the field of counseling as a whole.

Definition of Major Terms

This section provides definitions of terms utilized throughout the study. This researcher identified the following constructs to help provide clarity to the reader.

Thanatology: refers to the study of death through an interdisciplinary approach (Fonseca & Testoni, 2012).

Grief: "…is an emotional response. It is a normal, internalized reaction to the loss of a person, thing, or idea. It is our emotional response to loss" (Goldman, 2014, p. 26).

Bereavement: "…is a state of being. It is the state of having lost something, whether it be significant others, significant things, or our sense of self" (Goldman, 2014, p. 26).

Mourning: "…is what we do. It is taking the internal experience of grief and expressing it outside of ourselves. It is the cultural expression of grief, as seen in traditional or creative rituals" (Goldman, 2014, p. 26).

Adaptive Grieving Styles: a model that aims to address one's grief experience through individual cultural context representing the way in which a client copes with loss utilizing cognitive, emotional, and behavioral strategies (Harrawood et al., 2011).

Grief work: "…refers to an individual experiencing and expressing strong emotions related to a loss. The traditional viewpoint posits bereaved individuals must undergo grief work in order to recover from loss" (Doughty et al., 2011, p. 2).

Death work refers to any therapeutic or supportive work conducted by a helping professional surrounding death (often counselors, nurses, doctors, child life specialists, social workers and/or chaplains) (Chan & Tin, 2012, p. 900).

Child Bereavement Professional refers to any helping professional who has a background in mental health, counseling, psychology, or a related field and provides support and/or enhanced emotional well-being for children, young people and families in the field of bereavement, grief or loss.

Death Competence: According to Gamino and Ritter (2012), death competence refers to specialized skills in the areas of death, dying, and bereavement in order to work with clients effectively. Death competence "is a construct that not only describes an essential feature of the therapeutic repertoire of grief counselors but also constitutes an ethical imperative when working with the dying and the bereaved" (Gamino & Ritter, 2012, p. 24)

Pediatric Palliative Care: Dangel (2002) refers to pediatric palliative care as support for children, youth, and their families who are living with life-limiting conditions. The service allows for holistic care including physical, emotional, social, and spiritual health, providing families with respite services and support during or following a death.

Overview and Organization of Chapters

The research study is divided into five chapters: introduction, literature review, methodology, results, and discussion. Chapter one provided an introduction to the study, its purpose, and research questions. Chapter two explores the literature surrounding death, grief counseling, pediatric palliative care, and death education. Chapter three presents the methodology of the study further exploring the study's participants, procedures, research design, and data analysis procedures. Chapter four will showcase the results of this qualitative phenomenological study, while chapter five provides discussion on the limitations and implications for future practice.

CHAPTER TWO: LITERATURE REVIEW

Chapter two provides information on the context of the study. This researcher reviewed literature on death, grief, and bereavement as well as its implications for mental health. The focus of the study is on the experiences and perceived levels of preparedness for bereavement professionals, particularly in children's hospices. The sections in this chapter present a foundation for the study, as well as highlight challenges for mental health counselors in the area of bereavement work. Aspects of death, grief, and bereavement will be addressed through theoretical components, education/training, and the implications of loss on individuals, children, and mental health professionals.

Death, Grief, and Bereavement

Death is universal to the human condition, yet, individualistic in nature (Doughty & Hoskins, 2011). Although grief and bereavement are experienced by individuals every day, no two individuals experience them the same. Therefore, with such common, yet unique, experiences, it is not surprising that definitions of these concepts vary throughout the literature. According to the Report on Bereavement and Grief Research (2004), "bereavement refers to the loss of a loved one by death and grief refers to the distress resulting from bereavement" (p. 498). Grief was further recognized as a specific experience which may vary in intensity and include cognitive, emotional and/or social difficulties. Grief can also be experienced through non-death losses as well. These may include loss of relationship, job, or one's ability physically or cognitively (Hill et al., 2018). However, for the purposes of this study, grief will be explored through the context of death-related losses and working with the bereaved.

As cited by Servaty-Seib (2004), grief also included one's physical, spiritual, and behavioral states as well. In its most simplistic terms, grief is considered to be the emotional response to loss, while bereavement is the state one experiences after having lost someone or something (Goldman, 2014). Thanatology, the study of death, is a recent field focusing not only on the educational implications of death, but practical approaches as well (Fonseca & Testoni, 2012). It is important to recognize the distinctions of these terms surrounding death, as the concepts, and their definitions, provide an important framework from which the study is explored.

Evolution of Loss

Perceptions of grief and bereavement have changed over time. Although first proposed as a field of inquiry in 1903 by Metchnikoff, the field of thanatology did not take hold until the 1950s (Fonseca & Testoni, 2012). A lack of understanding and acceptance for death work resulted in a slow adaptation to the field of thanatology; however, the conclusion of World War II brought with it an increased focus on death (Parkes, 2002; Rolls & Payne, 2004). These early grief theories allowed for more insight into grief, loss, and bereavement.

Freud suggested that the study of mourning was important in order to interpret aspects of melancholia [clinical depression] in patients (Rando, 1995). He believed the best way for individuals to “complete” the process of mourning was through experiencing all needed feelings, and then allowing the ego to become free from that which was lost (Rando, 1995). In fact, if the bereaved individual maintained a relationship with their deceased loved one, it could be considered pathological (Hill et al., 2018). However, more current theories within thanatology have instead focused on maintaining one’s connection with the bereaved through theories on attachment, meaning-reconstruction, and continuing bonds (Servaty-Seib, 2004).

Classic Grief Theories

Just as the concepts of death, grief, and bereavement have evolved, so have grief theories. As mentioned above, Freud discussed grief in its relation to “letting go” of one’s emotional energy and finding ways to redirect it following the death of a loved one (Hill et al., 2018; Parkes, 2002). Yet, according to Doughty Horn et al. (2013), Bowlby’s theory, originally focused on attachment to caregivers, was later adapted to a more modern grief theory (Hill et al., 2018). Attachment theory included four phases to conceptualize the reactions of being bereaved in regard to the connections one has with others (Doughty et al., 2011). These phases included: numbing oneself, yearning for the deceased, disorganization/despair, and eventual reorganization as a way to “get over” grief (Doughty Horn et al., 2013; Hill et al., 2018; Servaty-Seib, 2004). Such stage and task theories, including that of Kubler-Ross’ five stages of grief, are considered well-known by the public, yet, do not possess empirical evidence regarding their effectiveness (Ober et al., 2012). In fact, these theories have been further criticized due to an implied universality when applying the theoretical implications to one’s grief work (Doughty et al., 2011).

Additional task/stage theories include both Worden and Rando’s theories of grief. According to Servaty-Seib (2004), Worden’s theory identified four tasks of mourning to help individuals accept a loss, work through their pain and emotions, and eventually “move on” from the deceased. Rando’s theory, however, posited that there are *processes* to mourning rather than tasks, and identified six “R’s” to grieving. These began with a recognition of the loss and ended with readjusting and reinvesting in life. According to Doughty and Hoskins (2011) stage theories provided a catalyst for conversations on death, and a structure for counselors to discuss the topic of death in practice. Nevertheless, these stage/task theories should be considered more descriptive in nature and used with caution by counselors. Implementation of these theories can often create a false understanding and insinuate a “correct” way to grieve through stages or the completion of tasks (Doughty & Hoskins, 2011; Servaty-Seib, 2004). The theoretical underpinnings presented in the literature designate a need for up-to-date and consistent grief education for mental health providers.

Modern Grief Theories

Modern theories of grief and bereavement are explored in the literature as well. The Dual Process Model of coping with bereavement, created by Stroebe and Schut, posited that individuals face both loss-oriented and restoration-oriented stressors after the death of a loved one (Servaty-Seib, 2004). The basis of this theory lies in an individual’s fluctuation between these two stressors while also incorporating periods of time where they may not focus on aspects of their grief at all (Doughty Horn et al., 2013; Servaty-Seib, 2004). Meaning reconstruction, as identified by Neimeyer, highlighted a constructivist and narrative approach in which individuals became co-authors of their stories in order to develop new meaning following the death of a loved one (Doughty Horn et al., 2013; Servaty-Seib, 2004). Meaning reconstruction closely aligns with the theory of existentialism in its approach to counseling, suggesting the understanding of a subjective reality rather than objective truth (Servaty-Seib, 2004).

According to Doughty and Hoskins (2011), adaptive grieving styles depicted a model for counselors to explain the unique experience of grievers utilizing a holistic view (personality, experience, and culture). The focus was on understanding the client’s culture to fully recognize and appreciate the individual grief experience. Adaptive grieving styles included intuitive, instrumental, and blended grieving, providing information on the way clients coped with a loss. “Counselors-in-training who receive death education particular to this model would have an entry level tool to work with a multitude of clients around the world" (Doughty & Hoskins, 2011, p. 28). Therefore, education on adaptive grieving styles may ultimately avoid creating dissonance; engaging in a way of grieving that is not true to one's natural adaptive grieving style. "It is important for counselors and counselors-in-training to recognize clients' natural adaptive styles and how they may or may not fit into cultural expectations" (Doughty & Hoskins, 2011, p. 32-33). The understanding of these implications aid in the practice of mental health counselors through a focus on multicultural implications.

Lastly, according to Doughty and Hoskins (2011), one of the most recent trends in bereavement work is continuing bonds. Continuing bonds theory focuses on ways for the bereaved to stay connected with the deceased by moving forward *with* their grief, instead of moving on *from* it. Continuing bonds suggests that individuals can continue a relationship with the deceased in a way that honors both the person and the relationship in a healthy way. This was congruent with the understanding of more modern grief theories.

The literature highlighted that no one theory can be applied collectively to grief issues (Cicchetti et al., 2016; Doughty et al., 2011). Instead, individual experiences, thoughts, and needs were paramount when working with the bereaved and dying (Doughty et al., 2011). Yet, due to the lack of standards around death education, training may continue to focus on theories not validated by empirical research (Ober et al., 2012). According to the American Counseling Association (2014), "counselors have a responsibility to the public to engage in counseling practices that are based on rigorous research methodologies" (p. 8). Therefore, by continuing to educate on classic grief theories without incorporating new research, strategies for practice, and professional/personal implications, graduate education may actually be undermining preparation for counselors in the areas of death, grief and loss (Ober et al., 2012). Ultimately, counselors need to recognize the unique and individualized nature to the grief and bereavement process (Cicchetti et al., 2016; Doughty et al., 2011; Doughty & Hoskins, 2011), signifying the importance for death education on aspects of theory, culture, intervention, and one's personal death awareness. Exploring theory may also assist in identifying appropriate strategies and therapeutic interventions when working with the bereaved.

Death Work

According to Chan and Tin (2012), death work takes many forms. These may include bereavement counseling, palliative care, working with individuals during/after a disaster, counseling those who are actively dying, and crisis intervention; all performed by a member of a helping profession. Although the experiences of death work vary, the significance of the work remains the same—to promote positive outcomes for grieving individuals (Hill et al., 2018). Due to the common experience of grief and bereavement, counselors will inevitability work with clients experiencing grief issues (Breen, 2011; Harrawood et al., 2011; McClatchey & King, 2015). Furthermore, since the nature of bereavement and grief is complex, the way in which counselors approach death work is important to explore and understand.

Grief is considered both a universal and critical experience in life (Cicchetti et al., 2016; Doughty Horn et al., 2013; Dunphy & Schniering, 2009; Hill et al., 2018; Wilson et al., 2017), consequently, by simply focusing on a client's expression of grief, counselors may simply be scratching the surface (Servaty-Seib, 2004). As grief is not solely related to death losses (Humphrey, 1993), counselors need to gain a deeper understanding of the implications of grief, bereavement, and mourning to help support clients through their grief journeys (Servaty-Seib, 2004). The literature continued to present information on bereavement and grief as constructs; yet, there remained a noticeable gap on education/training for grief work in counseling, and thus the effects of this work on mental health professionals (Dunphy & Schniering, 2009; Harrawood et al., 2011; Wass, 2004).

Death Education

Death is recognized as an unavoidable part of life; however, thoughts, reactions and issues of death are still often avoided by individuals and society (Wass, 2004). Feelings around death may bring discomfort due to having to face one's mortality—an experience Yalom found comparable to 'staring at the sun' (Yalom, 2008). This avoidance of death also continues at the an institutional level as death education is not consistently present or considered a standard in curriculum (Cicchetti et al., 2016; Doughty Horn et al., 2013; Hill et al., 2018; Ober et al., 2012), particularly for mental health professionals. Therefore, consistent education and experienced supervision in death work might help to expand the reach of mental health practitioners in this area (Prado & Waterman, 2017).

Death education is vital for those in the helping professions (Harrawood et al., 2011; Servaty-Seib & Parikh, 2014; Wass, 2004). According to Doughty et al. (2011), counselors need to be prepared to work with clients and their unique grief issues. As such, knowledge and skills in death education are critical for counselors to help clients understand, adjust and explore grief and loss (Ober et al., 2012). In fact, Doughty et al. (2011) argued that elements of grief and loss are most likely present in all client encounters already due to the universal nature of grief. Although a great deal of literature exists in the area of death, dying, and bereavement, there is a lack of information regarding its inclusion into curricula for most helping professions, including that of counseling, psychology and teaching.

Wass (2004) further identified gaps that remain between death literature and practice. Wass noted that without acting on practical implications for grief and loss education noted within the literature, one further perpetuates a researcher-practitioner gap. Stated more plainly, research on the need for death education continues to be published; however, standard practices to death education are not being implemented (Hill et al., 2018). Although counselors may have a basic understanding of the conceptualization of death, this does not equate to professional training when working with clients (Ober et al., 2012). Thus, there remains a need to integrate the literature into programming, education, and clinical practice.

Training

Literature on consistent training or educational opportunities in death, grief, and bereavement remains brief. Information present on current training opportunities in death work reported that most individuals participated in seminars and/or continuing education workshops rather than formal graduate programming (Hannon & Hunt, 2015; Wass, 2004). Furthermore, when death content was available through graduate studies, it was offered through limited lectures, dissatisfying the need for students to be prepared for grief work, bereavement counseling, or work with the dying (Cicchetti et al., 2016; Wass, 2004). The lack of research highlights a need for more information on education/training for mental health professionals. Additionally, the inclusion of death education in short formats, such as with lectures or seminars, does not allow for exploration regarding professional or personal feelings of death.

According to Wass (2004), short educational opportunities do not include opportunities to explore one's personal development, death anxiety, or comfort working in the area of bereavement. As such, current models in counseling education focus more on issues of traumatic bereavement or complicated grief, rather than familiarity and practical applications regarding normative bereavement. It has been found that beginning counselors further reported feeling uncomfortable discussing topics related to grief and loss made compared to other presenting problems (Doughty Horn et al., 2013), denoting the significance for exploration into bereavement work. Furthermore, current death education focuses on knowledge and skills; however, the emotional and existential challenges of death work also need to be explored to incorporate competencies, information, and interventions into one's practice (Chan & Tin, 2012).

There have been a variety of studies regarding grief competency and death education. A study from Ober et al. (2012) on counselors' training, experience, and competencies in grief counseling asked participants to identify familiarity with grief theories. Most participants in the study reported a knowledge of Kubler-Ross' five stages of grief, but little knowledge regarding other theories, including those related to meaning reconstruction or attachment. The significance of these findings spoke to the importance of death education as the literature suggested that stage theories may create a false understanding of how one should grieve (Doughty & Hoskins, 2011; Servaty-Seib, 2004).

To this point, Kubler-Ross' theory was constructed based on research from individuals who were living with terminal illnesses (Doughty et al., 2011), making it difficult to disseminate the findings for those who are bereaved. Hill et al. (2018) suggested that grief education and training include theories related to meaning making/meaning reconstruction, the dual process model, attachment, and adaptive grieving styles in addition to classical grief theories; important considerations for curricula inclusion in counselor education. In fact, implications for future research included an emphasis on grief counseling training to effectively work with clients, and an understanding of current grief approaches to counter the traditional stage theories currently widespread through education (Ober et al., 2012). A focus solely on theory, however, diminishes the importance for personal death awareness, boundaries and strategies for best practice for counselors (Chan & Tin, 2012), important considerations for counselor educators.

The literature highlighted the importance of specific information on grief and loss, addressing the difference between personal familiarity with grief and that of professional knowledge (Ober et al., 2012). Studies have shown that levels of discomfort were predictors of personal fear of death indicating importance for the exploration of death anxiety (Wass, 2004); additionally, it was found that counselors who had an understanding of their own death attitudes and self-awareness reported more success discussing and expressing personal feelings of loss with clients (Ober et al., 2012). Individuals who had death education in graduate-level programming reported feeling more competent in grief work (Hill et al., 2018).

Education and Training in Counselor Education

Multiple articles identified a lack of competence in working with bereavement, as clinicians often reported a lack of knowledge with clients facing loss (Black, 2007; Kramer et al., 2003; Stewart et al., 2000). However, as all individuals will experience loss, it is inevitable that all counselors will be working with these issues. Yet, grief is not included as a core component in counseling curriculum (Harrawood et al., 2011; Ober et al., 2012). Although the American Counseling Association (ACA) 2014 code of ethics highlights the importance of proper training in the determination of professional competence (ACA, 2014), the Council for Accreditation of Counseling and Related Educational Programs (CACREP) does not require course work specifically related to grief and loss (Cicchetti et al., 2016; Doughty & Hoskins, 2011; Hill et al., 2018; Ober et al., 2012).

Consequently, counselors-in-training who had taken death education courses were found to exhibit more openness to death constructs and less fear when addressing issues related to grief and loss with clients (Doughty Horn et al., 2013). In a survey conducted by Ober et al. (2012), 91% of respondents indicated that grief counseling training was needed or should be required.

Additional findings demonstrated a decrease in death anxiety and an increase in confidence/competence with death work after engaging in death education or training (Hill et al., 2018; McClatchey & King, 2015). In a randomly selected survey of American Counseling Association (ACA) members, those who had participated in grief workshops, *past* their graduate education, were found to have reduced levels of anxiety in working with death-related issues (Doughty Horn et al., 2013). McClatchey and King (2015) found that students who had taken a death, dying, and bereavement course had different scores at the post-test than students in the comparison group. Students in the class experienced a significant lowering of fear of death and anxiety symptoms than those students who did not participate in the death education class. Additionally, in a study of nursing students following death education training, results showed statistically significant findings on both positive student attitudes toward death and caring for dying patients (Cerit, 2019).

As emphasized previously, knowledge and skill development in death work is needed, but often lacking (Christ & Sormanti, 1999; Doughty Horn et al., 2013). The literature highlights the risk of burnout, compassion fatigue, and secondary traumatization among helping professionals in their work with death and dying (Chan & Tin, 2012). Gaining knowledge and skills in this area may help to reduce stress for professionals and enhance their ability to cope (Chan & Tin, 2012; Hill et al., 2018), while also improving one’s comfort level, case conceptualization, and treatment planning (Ober et al., 2012). There exists a need for identifying grief competency standards within the counseling field (Hill et al., 2018). Therefore, the proposed study focuses on the perceived levels of preparedness and lived experiences of bereavement workers to address concerns and gaps noted within the literature.

Ethical Implications

Counselors have an obligation to practice ethically. According to the ACA's 2014 code of ethics, counselors need to be prepared to work with their clients within one's scope of practice (ACA, 2014; Hill et al., 2018). Therefore, proper education, training and supervision is needed before engaging in counseling, and new specialty areas of practice (ACA, 2014). Additionally, another ethical consideration is that of continuing education. Continuing education is necessary to remain current regarding information and practical applications for best practice in working with diverse populations (ACA, 2014).

The ACA code of ethics further states that multicultural counseling competency is a requirement regardless of one's specialty area, and counselors need to "gain knowledge, personal awareness, sensitivity, dispositions, and skills pertinent to being a culturally competent counselor in working with a diverse client population" (ACA, 2014, p. 8). A unique ethical consideration also needs to be taken into account when counseling clients with terminal illnesses as clients may disclose feelings of wanting to hasten their death (ACA, 2014) due to symptoms, feelings of meaninglessness, and suffering. Ethical implications provide an important understanding regarding a need for death education. Recommendations for grief and loss education include grief theories, cultural implications, individual grieving styles, normative and maladaptive coping, awareness of personal and professional implications on death, and counseling techniques (Doughty Horn et al., 2013). Ultimately, individuals who are working with death, dying, and bereavement need to be aware of death competence and the need for additional education.

Although a great deal of literature exists in the area of death, dying, and bereavement, it has not permeated the curricula of most helping professions (Cicchetti et al., 2016; Doughty et al., 2011; Hill et al., 2018; Ober et al., 2012; Wass, 2004). The numerous studies indicating the need for inclusion of grief education and standards highlight a research-practitioner gap between the literature and practice. In fact, Wass (2004) posited that the literature will simply continue to be accessed by other researchers specific to the field of thanatology if there is not a greater push to apply the research to professional practice.

Impact on Clinicians

Grief and bereavement have an impact on clinicians as well. Working with clients in this population can bring both cognitive and emotional implications (Hill et al., 2018). As the counselor is crucial in the therapeutic process (Chan & Tin, 2012; Crunk & Barden, 2017), one's personal attitudes on death and bereavement may have an effect on counseling work, and ultimately the therapeutic relationship (Chan & Tin, 2012). Additionally, the impact of grief and bereavement work can affect the clinician's overall wellness, and risk compassion fatigue, burnout, and secondary trauma (Cacciatore et al., 2015; Chan & Tin, 2012). Therefore, it is important for clinicians to understand and cope with their own loss experiences through an awareness of their own death attitudes (Black, 2007). Having a grasp on these areas will ultimately promote not only the client's wellness but work to maintain the overall wellness of the counselor as well (Hill et al., 2018).

Although the literature explores the implications of grief and bereavement, there are few studies that explore the experiences of professional bereavement counselors (Dunphy & Schniering, 2009; Kouriatis & Brown, 2011). Therefore, there exists a need for qualitative research to explore the implications of death education (Wass, 2004), particularly for individuals working in bereavement. Literature that does exist in this area explored the uniqueness of both working with bereavement and experiencing it on a personal level (Kouriatis & Brown, 2011).

Although underexplored, Dunphy and Schniering (2009) highlight the significance of this for counselors, and the potential for serving clients when a clinician has had their own grief history.

However, as noted by Worden (2009), “If it has been adequately integrated, the counselor’s experience with a similar loss can be beneficial and useful in work with the client” (p. 252). The ability for a clinician to engage in their own death work is important not only for ethical practice, but to identify any potential blind spots as well (Dunphy & Schniering, 2009; Worden, 2009). Worden (2009) further posited that working with the bereaved can have a personal impact on mental health professionals in three ways. First, he noted that through counseling the bereaved it makes one aware of their own losses. Second, through an exploration of one’s personal losses, the counselor is then able to identify resources that were, or were not helpful, to the counselor’s own grief process. Third, being exposed to one’s own grief brings insight into the clinician’s limitations for working with grief and bereavement, allowing them to make ethically informed decisions. Important considerations for mental health practitioners.

Cultural Implications

The significance of the subject matter relates to multicultural humility and awareness needs as well. Multicultural humility is discussed in-depth in relation to the work of counselors and included with the ACA code of ethics (2014); however, the impact of one’s death awareness and anxiety is not well identified. Therefore, counselors may need to be aware of their own biases and privilege regarding their own death anxiety, spirituality, and existence (Gamino & Ritter, 2012; Harrawood et al., 2011), due to potential implications with clients. Additionally, the significance of the client’s mortality has an impact on the counseling relationship (Manis & Bodenhorn, 2006) and therefore needs to be taken into consideration when working with this population.

According to Doughty and Hoskins (2011), an emphasis on individual differences allows for an understanding between healthy and unhealthy reactions to grief. Therefore, "…it becomes imperative for counselors and counselors-in-training to conceptualize their clients from a socio-cultural globally sensitive, and intra-personal perspective" (Doughty & Hoskins, 2011, p. 27). Yet, there remains an expectation for counselors to engage in culturally appropriate practice and remain within one's scope of practice (Doughty & Hoskins, 2011; Cicchetti et al., 2016; ACA, 2014) without a standardization for grief counseling practice. Therefore, education and preparation that includes cultural implications, grief theory, personal death awareness and interventions for practice is needed to work with issues of grief and loss, and the bereaved (Doughty & Hoskins, 2011; Doughty Horn et al., 2013; Hill et al., 2018). It is important for counselor educators to recognize how culture impact one's grief responses as well as current trends in the field to assist with preparing counselors to work with these aspects of grief work (Doughty & Hoskins, 2011).

Grief counseling requires that counselors explore the client's culture and how that may impact the grieving process (Doughty & Hoskins, 2011). As Doughty and Hoskins (2011) stated, "Educating helping professionals about a multicultural and trans-culturally sensitive model for bereavement counseling…can be powerful" (p. 34). These implications are especially important when working with the unique population and experiences of child death or bereavement. Although education specific to this area is lacking, the United Kingdom has identified child death and bereavement as a significant area of focus (Bagatell et al., 2002; Mash & Lloyd-Williams, 2006; Rolls & Payne, 2004; 2007). Research suggests that while the United Kingdom has over 50 children's hospices (*About Us*, n.d.-a; *About Us*, n.d.-b) the United States has three dedicated children's facilities out of over 3,000 hospice programs (Morgan, 2009).

Ultimately, death crosses cultural boundaries (Pentaris, 2011; Rolls & Payne, 2004). Thus, grief and loss affects each individual's perceptions of death differently (Doughty & Hoskins, 2011). More specifically, the way individuals perceive death relies largely on cultural considerations due to varying beliefs and customs (Pentaris, 2011). This is true for end-of-life support as well. According to Wass (2004), education in death and bereavement has led to advances in the medical field when caring for the terminally ill. Although death education was developed primarily by nurses to improve overall care, perhaps its biggest accomplishment was through the development of hospice programs (Wass, 2004). Pediatric palliative care specifically has been prevalent in healthcare, yet underexplored in the literature (Morgan, 2009).

Children's Hospices in the United Kingdom

Worldwide, the United Kingdom is considered a pioneer in children's hospice work (Price et al., 2013) as there is an increased focus on death, dying, and bereavement (Kirk & Pritchard, 2012). This is in part due to an implicit understanding of how bereavement impacts childhood (Rolls & Payne, 2003; 2004) as well as the fact that children's hospices in the United Kingdom are considered central to quality care and the palliative care provision (Kirk & Pritchard, 2012). To this end, free-standing children's hospices are considered rare in European countries outside of the U.K. (Dangel, 2002). When comparing these services to other countries, particularly the United States, the United Kingdom has upwards of 50 children's hospices (*About Us*, n.d.-a; *Childrens Respite & Hospice Homes*, n.d.; House et al., n.d.), while the United States has only three in full service (*About Us*, n.d.-a; *Childrens Respite & Hospice Homes*, n.d.). Consequently, pediatric palliative care services are considered well-developed in the United Kingdom (Dangel, 2002).

According to Doughty and Hoskins (2011), “Each society has traditions and rituals that provide structure to the bereavement experience and outline expected behaviors” (p. 28). In the United Kingdom, pediatric hospice facilities offer both respite and bereavement support to children with life-limiting conditions and their families—conditions that signify no practical hope for a cure, and unfortunately result in the death of a child from their condition (Dangel, 2002). Therefore, hospice facilities provide support to those living with life-threatening conditions and with the death of a child. As cited by Dangel (2002), the following groups are broadly defined regarding access to children’s hospice care:

> Group 1. Life-threatening conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails. Children in long-term remission or following successful curative treatment are not included. Examples include cancer, irreversible organ failure of heart, liver, or kidney.
>
> Group 2. Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible. Examples include cystic fibrosis and muscular dystrophy.
>
> Group 3. Progressive conditions without curative treatment options, for which treatment is exclusively palliative and commonly may extend over many years. Examples include Batten's disease and the mucopolysaccharidoses.
>
> Group 4. Conditions with severe neurological disability, which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not usually considered progressive. Examples include severe multiple disabilities such as

> those that can follow brain or spinal cord injuries (including some children with severe cerebral palsy) (p. 160).

These categories highlight some of the situations that may bring a child to hospice. Additionally, it is important to note that medical care continues while children are in hospice programs, should they choose. Children's hospice staff work with hospitals to provide multi-disciplinary, holistic care that best meets the needs of the child and family (Mash & Lloyd-Williams, 2006). This may include support emotionally, physically, socially, and spiritually for the child and family (Dangel, 2002). However, although counseling for bereaved children, youth, and families has been identified as impactful from those receiving it (Kirk & Pritchard, 2012), there are no formal standards for grief support (Hill et al., 2018).

Theoretical Foundation

Existential theory helped to form the foundation of this study. Existentialism emphasizes the four givens of existence and a focus on a "search for meaning" and "self-actualization" (McClatchey & King, 2015). It is suggested that death work demands not only the knowledge and skills of helping professionals but also personal preparation for death, dying, and bereavement (Chan & Tin, 2012). Helping professionals are often reluctant to discuss death, and have a hard time navigating their own death attitudes/anxieties when faced with death-related client situations (McClatchey & King, 2015). Therefore, existentialism posits that individuals look at the realities of the human condition as a way to find choice and meaning.

Existentialism further explores the need for clients to discover, or rediscover, their purpose and meaning for existence (Lemay & Wilson, 2008); in doing so, the therapeutic process takes an in-depth look at the way in which the client views their world (Alegria et al., 2016). The four ways in which the client connects and experiences their world (relation to him/herself, others, nature, and spiritually) allow for opportunities to explore value, meaning, purpose and freedom within those limitations (Sørensen et al., 2018). As noted previously, existentialism suggests that one cannot simply be a passive observer of their experience; instead, they must take ownership and actively engage in this restructuring and of their being-in-the-world, which can produce anxiety and uncertainty (Colosimo et al., 2018; Manis & Bodenhorn, 2006; Sørensen et al., 2018; Yalom, 2008).

Existentialism further states that all individuals have certain inevitabilities of their human condition (Alegria et al., 2016; Eliason et al., 2010; Yalom, 1980), yet, if these aren't explored through an individual and cultural lens for each client, this can lead to generalizations which may impact the client and counseling relationship (Hoffman & Cleare-Hoffman, 2011). Therefore, the inevitability of death needs to be explored not only by clients, but also by clinicians to effectively work with clients in practice (Chan & Tin, 2012). Through the process of healing, practitioners may face the same existential questions as their dying or bereaved clients, therefore, it is important for counselors to acknowledge their own personal death awareness and existential concerns. Through this understanding and acknowledgement, counselors will be better able to help clients in their search for meaning (Chan & Tin, 2012).

Summary

Death and bereavement are inevitable to the human experience (Doughty Horn et al., 2013; Dunphy & Schniering, 2009; Hill et al., 2018; Wilson et al., 2017). Thus, for ethical practice, counselors need to be prepared to work with issues related to grief and loss (Doughty et al., 2011). Due to sparse and inconsistent bereavement education, counselors often reported feeling ill-prepared to work with issues related to death, grief and bereavement (Chan & Tin, 2012; Doughty Horn et al., 2013; Ober et al., 2012). Furthermore, issues related to bereavement work have implications for therapists; yet are underexplored in the literature (Dunphy & Schniering, 2009; Kouriatis & Brown, 2011). Finally, cultural implications are paramount in grief work, noting the significant differences on the focus for child bereavement between the United States and United Kingdom. Therefore, the inclusion of internationally relevant death education for bereavement training is warranted (Doughty & Hoskins, 2011), representing a need for the proposed study on the lived experiences of child bereavement workers in the United Kingdom. Chapter three presents information on the methodology of the study.

CHAPTER THREE: METHODOLOGY

Chapter three explores the methodology of this research study. Information is presented on strategies utilized by this researcher to gain a deeper understanding of the lived experiences of child bereavement professionals in the United Kingdom. This researcher utilized a qualitative, phenomenological research design with semi-structured interviews to address the research question. The following study information is included within the chapter: introduction, research design, theoretical foundation, participants, sampling, procedures, data analysis, trustworthiness/credibility, and limitations.

Introduction

The purpose of this study is to explore the feelings, experiences, and education of bereavement support professionals working in children's hospices in the United Kingdom. Therefore, phenomenological analysis was utilized to understand the depth and meaning of the experiences under study (Hays & Singh, 2012). In conjunction with the foundations of existential theory, a particular focus was on the givens of one’s existence, both personally and professionally, and the way in which meaning was constructed. Utilizing a phenomenological-qualitative design, this researcher sought to gain a better understanding of bereavement work through the perceptions and experiences of individuals who worked directly with issues of death and dying in children’s hospices. Due to the increased number of children’s hospices in the United Kingdom compared to the United States (*About Us*, n.d.-a), the lived experiences of child bereavement professionals in the United Kingdom were explored.

Research Design

This researcher utilized a phenomenological research design for this study. Phenomenology focuses on the discovery of participants’ lived experiences and finding commonalities across those experiences (Hays & Singh, 2012). This design fits the research study due to the exploration of individuals' perceptions in the field of child bereavement hospice work. A common element to all qualitative inquiry is exploring how people make sense of their world (Patton, 2015). Therefore, the characteristics of this study best represent a phenomenological design as the goal was to understand and explore not only the lived experiences, but also the depth and meaning of those experiences (Hays & Singh, 2012).

Research Paradigm(s)

A social constructivism paradigm provides the underlying framework for the study. Social constructivism, also known as postmodernism, is "a belief system that assumes that 'universal truth' cannot exist because there are multiple contextual perspectives and subjective voices that can label truth in scientific pursuit" (Hays & Singh, 2012, p.41). A major tenant of this paradigm is the exploration and construction of knowledge through connections with others and their lived experiences, while acknowledging subjectivity (Hays & Singh, 2012; Patton, 2015). It is through this lens that this researcher looked to address the research question and analyze interview data.

According to Hays and Singh (2012) there are five core philosophies of science used to explain a research paradigm (ontology, epistemology, axiology, rhetoric, and methodology). This researcher explored each philosophy with regard to the present study on the lived experiences of child bereavement workers. *Ontology* recognizes that all participants' experiences are unique, and multiple realities of bereavement work may occur for each interviewee. Additionally, that these experiences may also be influenced by societal and cultural views on death. *Epistemology* assumes that the creation of knowledge occurs between the participants and the researcher when exploring the phenomenon, and that the researcher is included in the construction of knowledge through the process. *Axiology* further emphasizes the significance of both the researcher and the individuals taking part in the study in accordance with location (children's hospices in the U.K.) in order to maintain a naturalistic setting. *Rhetoric* makes known that the child bereavement workers' voices are paramount when exploring data and reporting the findings, including the analysis of the data. Additionally, the researcher's reflexivity and chosen research setting, were utilized in conceptualizing the results. Finally, the *methodology* utilized by this researcher was chosen to address the research question through a collaborative nature and to identify the most appropriate methodology based on the study. The researcher paradigms were combined with the theoretical framework as a lens through which to view the study.

Theoretical Framework

The nature of grief, bereavement, and death work brings about a natural inquiry into the meaning of life and one's purpose. When faced with the givens of the human condition, especially as it relates to the inevitability of death, meaning construction can take new forms both personally and professionally. To that end, the significance of exploring meaning and purpose is not only present in counseling/bereavement work, but also life itself. Therefore, due to the nature of this qualitative inquiry, this researcher rooted the theoretical framework of the study in existential theory.

The history of existentialism holds a great deal of philosophical underpinnings. As a part of the third wave of humanistic theories, the focus shifted to exploring emotions, the therapeutic alliance and the meaning of one's existence (Seligman & Reichenberg, 2014; Shahar & Schiller, 2016). Individuals such as Rollo May, Soren Kierkegaard, Friedrich Nietzsche, Jean-Paul Sartre, Martin Heidegger, Martin Buber, Viktor Frankl and Irvin Yalom are just some of the individuals who have contributed to the development of this theory (Alegria et al., 2016; Fernando, 2007;

Hoffman et al., 2015; Seligman & Reichenberg, 2014). There is not one sole founder of existentialism; therefore, the differing viewpoints among the contributors has allowed for a more fluid approach, which has continued to grow through a collection of beliefs, values and perspectives of each individual (Correia et al., 2017; Hoffman et al., 2015; Schneider, 2016).

The focus of existential theory lies in the questions: What is the meaning of life? What is the purpose of our existence? (Seligman & Reichenberg, 2014). These inquiries into the human condition highlight some of the main components of existentialism (Vos et al., 2015). The questions signify a desire for individuals to explore their meaning and purpose in the world. Through the lens of existential theory, humans are continuously faced with the challenges of existence (Alegria et al., 2016; Yalom, 2008). Existentialism posits that the four givens of the human condition: the inevitability of death, isolation, meaninglessness, and freedom are all the result of being alive (Eliason et al., 2010; Georganda, 2016; Grădinaru, 2017; Seligman & Reichenberg, 2014). These "ultimate concerns" or "givens" shed light on the commonalities that all humans face and the anxieties that come as a result (Wadlington, 2017; Yalom, 1980, 2008). Consequently, the way in which one makes sense of these realities allows for meaning, purpose, and choice.

Existential theory is not looked at for its specific interventions. Instead, the theory provides a framework for utilizing the givens of the human condition as a way to decrease psychological distress and discover meaning (Alegria et al., 2016; Correia et al., 2017; Yalom, 2008). Although this has been useful in its work with clients, this also holds true for professionals in the helping professions in the way they may construct meaning of their work. Moreover, existentialism is not simply an intervention to use, but a holistic and philosophical foundation from which counselors can plant their roots—shifting the focus from intervention to meaning construction and the purpose of life (Kasavina, 2017; Seligman & Reichenberg, 2014). By acknowledging one's life and being-in-the world, both critical aspects of existential theory, it creates a deeper level of authenticity for individuals with an increased focus on the here-and-now (Shahar & Schiller, 2016; Worrell, 2019). This existential framework, in conjunction with a social constructivism lens, provides a foundation from which to explore the study.

Research Question

The purpose of a qualitative research question is to explore or describe various experiences (Hays & Singh, 2012). Therefore, the question constructed for this qualitative inquiry was focused on exploring the lived experiences of individuals working in children's hospices in the U.K. The research question for this study was:

> "What are the experiences and perceived levels of preparedness of bereavement professionals working with bereaved children, families, and young people?"

Objectives to Explore

In addition to the research question, the following objectives were also identified for exploration in the study:

1. Bereavement support professionals' perceptions of their work on both a professional and personal level.
2. Specific training and other contributory factors that bereavement support professionals feel most important and useful in their work.
3. Content and practices of how counselor educators and supervisors prepare students to address the effects of grief and loss as they relate to children, young people, and the wider family system.

4. Bereavement professionals training experiences related to issues of diversity and cultural differences.

Participants

Sample selection is purposeful when conducting qualitative research (Patton, 2015) and requires that the researcher develop certain criteria for the sample to allow for rich information from the phenomenon being studied (Hays & Singh, 2012). Therefore, this researcher utilized purposeful sampling to identify participants who were bereavement workers in children's hospices in the U.K. Participants were obtained through a combination of convenience and snowball sampling. Convenience sampling provides ease of access to a population, while snowball sampling creates a networking effect to gain more individuals into the sample based on connection (Hays & Singh, 2012). This researcher had previous collaborations with U.K. child bereavement training sites, and developed a professional relationship with Paula Abramson, the founder of Bereavement Training International. As this researcher is not located in the U.K., a preexisting professional relationship with Paula allowed for connection to leaders at children's hospices within the United Kingdom to determine eligibility and interest in the study.

Participants in this study consisted of child bereavement professionals in children's hospices across the 33 boroughs of London, England, United Kingdom. The included research sites were from a network of Children's Hospices around London (CHaL)—a group of six hospices that support children and young people with life-limiting and life-threatening conditions and their families (*About Us*, n.d.-b). Through the convenience and snowball sampling process, Paula was able to identify hospices in the area that could be contacted for potential interest in the study. Upon obtaining IRB approval, this researcher sent the following documents to Paula for dissemination to each hospice: interview questions (appendix A), IRB approval (appendix B), informed consent (appendix D), and the recruitment email (appendix E). Upon sending the study and recruitment information to leadership at the various children's hospices in the U.K., Paula also encouraged staff to inform the researcher(s) of additional individuals/hospices who might be interested in participating in the study based on inclusion criteria.

Sample Size

A goal set by this researcher was 15-20 participants for this study. According to Flynn and Korcuska (2018), the appropriate number of participants can range significantly in phenomenological research. Thus, the overall number in one's sample size needs to be based on the research purpose itself (Hays & Singh, 2012). Due to the specific nature of this study (researchers traveling to the U.K. to conduct interviews at various children's hospice facilities), this researcher established the goal for recruitment to allow for representation and saturation. Stated more plainly, this researcher focused on gaining depth rather than breadth with the phenomenon under study, as is a goal of qualitative work (Hays & Singh, 2012).

Once information on the study was received and returned by each hospice, individuals were invited to participate if the following inclusion criteria were met: (a) individuals were currently employed at a children's hospice in the U.K., (b) the individual had a background in mental health, counseling, psychology or a related field, and (c) the individual's role at the hospice involved providing support and/or enhanced emotional well-being for children, young people and families. A total of 15 individuals were recruited from six different children's hospices to obtain saturation.

Procedures

Prior to start of the study, coordination occurred among the research team to discuss the feasibility and need of a study in this area of child bereavement. Thus, in coordination with Paula

Abramson, children's hospices were contacted to gain interest in potentially engaging in a study about child bereavement professionals. Interest and permission were obtained from each hospice's leadership board for this researcher to recruit staff and conduct interviews on site at each location. Conducting the interviews at each hospice in the U.K. was important to this researcher in order to maintain a naturalistic setting. This was particularly significant due to the nature of this study and allowed the researcher(s) to observe the way in which participants interacted in their direct environment (Hays & Singh, 2012).

This researcher received approval from the Institutional Review Board at North Dakota State University prior to contacting participants and conducting interviews (see appendix B). IRB approval included this researcher, NDSU faculty Dr. Brenda Hall, and Paula Abramson, founder of Bereavement Training International in the U.K. Once IRB approval was obtained, this researcher provided the recruitment email, informed consent, IRB approval documentation, and interview questions to Paula for dissemination to her contacts at each children's hospice. An additional IRB form was added to include Dr. Carol Buchholz-Holland as a co-researcher (see appendix C).

Child bereavement workers at each hospice were then sent a recruitment email (see appendix E) including attachments containing the documents noted above. If participants were interested in participating in the study, they were given Paula's contact information due to ease of communicating with someone directly in the United Kingdom. Participants were then screened based on inclusion criteria. In addition to recruitment, Paula's involvement in the study assisted with cultural insights and awareness as to noted differences between the United States and United Kingdom. Her participation allowed for a more fluid process for coordinating with potential participants due to the time difference, her familiarity with bereavement and children's hospice facilities in the U.K., and challenges to international communication. Paula's experience was also utilized throughout data analysis to assist with language and meaning with participants' word choice in order to assist with the trustworthiness of the study.

Data Collection

As noted previously, participants were given the informed consent document within the recruitment email prior to interviews. This allowed participants to explore the purpose of the study, what they would be asked to do, and risks/benefits (see appendix D). Semi-structured interviews were created by this researcher and reviewed by other members of the research team. Once participants indicated interest and were screened, Paula coordinated interview times with participants onsite at each hospice. Interviews were conducted by this researcher, Dr. Brenda Hall, and Paula Abramson. Due to the international travel of this researcher and NDSU faculty, data collection took place during January 5th-28th, 2020.

Upon this researcher and Dr. Hall arriving in the U.K., time was spent with Paula to identify any pertinent information needed prior to the interviews. This included specifics about travel to and from each hospice and cultural considerations. Once the researcher(s) arrived at each location to conduct interviews, staff provided a tour of their hospice facilities. A private area was then setup within each hospice for the participants' interviews to ensure confidentiality.

Prior to the start of each interview, informed consent was reviewed and discussed with the participants. The informed consent document outlined all aspects of the study. Once participants chose to take part in the study, they were then asked to sign informed consent. After the consent form was signed, participants engaged in individual, audio-recorded, semi-structured interviews. Participants were informed they could stop the interview at any time without penalty. In order to maintain confidentiality, the follow steps were taken: (a) interviews took place in a quiet, private location within each hospice, (b) demographic information collected did not include specific personal identifiable information, (c) specific hospice locations where each participant worked would not be identified in the study (d) all interviews were given a random number code at the start of each recording for identification, and (e) interviews were stored in a secure place (under lock and key) so that only the researchers would have access. Data was transcribed and deidentification occurred. To further maintain confidentiality and help with analysis, participants were each given a pseudonym during transcription.

Interview Questions

This researcher developed the interview questions in order to explore the lived experiences of child bereavement professionals in the U.K. Once the researcher created the initial questions, they were brought to Dr. Brenda Hall and Paula Abramson for consultation. This occurred to ensure reliability based on the study information, expertise/experience in the field, and cultural considerations. The goal was to make sure the questions addressed the purpose of the study. There were five primary questions developed, along with secondary questions depending on topic (see appendix A). Demographic information was also collected including educational background, licensure, certifications, and years in bereavement work.

Participants were asked the interview questions in a semi-structured/in-depth interview format. Although this researcher developed specific questions prior to the interview, follow-up questions were added as needed during the interviews in order to capture the essence of each person’s experience. According to Hays and Singh (2012), semi-structured interviews are beneficial as they allow for supplemental questions to fully explore the participant’s experience. Similarly, a semi-structured interview process is considered more person-centered and culturally appropriate, as it allows for more of the participant’s own voice. At the end of each interview, participants were also given an opportunity to include information they may not have been asked by the researcher(s). Hays and Singh describe this as a strong closing, and an opportunity to give participants the final say regarding their experiences. There were 15 total participants across six children's hospices who signed consent and engaged in the study. Interviews lasted between 35 minutes to 1hr 15 minutes.

Data Analysis

The purpose of this study was to explore the lived experiences of bereavement workers in children's hospices in the U.K. After the collection of data was completed, this researcher began the data analysis process. Phenomenological analysis was utilized to examine interview data to explore the meaning and essence of participants' experiences (Hays & Singh, 2012). Moustaka's (1994) modification of the Stevick-Colaizzi-Keen method was then utilized for data analysis. According to Moustakas (1994), there are four main steps to this method. The first step is for the researcher to obtain a thorough description of his/her own experience through bracketing.

Bracketing occurs prior to data analysis to address the researcher's assumptions, beliefs and experiences about the phenomenon (Hays & Singh, 2012). This is helpful not only in increasing the rigor of the study, but also in creating deeper levels of reflection throughout all aspects of the project (Tufford & Newman, 2010). This researcher identified and bracketed her experiences with the study phenomenon utilizing a reflexivity statement prior to reviewing transcripts. The researcher specifically reflected on her personal and professional experiences in the field of bereavement, including a particular focus on this work with children and families. Any prejudgments present about the phenomenon being explored were also included in the researcher's process. The researcher's reflexivity statement is included in this chapter.

Although bracketing was completed prior to data analysis, it is important for this researcher to maintain reflexivity throughout all aspects of the study. According to McNarry et al. (2019) in a phenomenological approach, the phenomenon being explored is not separate from one's human consciousness and experience; instead, it forms part of one's subjectivity of the phenomenon. Subjectivity is a critical aspect of qualitative research as it is the researcher's internal understanding of the phenomenon (Hays & Singh, 2012). Furthermore, subjectivity should be considered positive to one's work as it brings the researcher closer to the study in a way to understand the phenomenon more intimately (Hays & Singh, 2012). As referenced, the ability of the researcher to completely bracket all assumptions is impossible, as one's theories, meanings, and assumptions about the world are a part of everyday life (McNarry et al., 2019). Thus, it is imperative that this researcher maintain consistently involved in reflexive practice throughout the process.

The second part of Moustaka's (1994) modification of the Stevick-Colaizzi-Keen method involved completing a number of steps with each transcript. The researcher became connected with the data as a holistic set, reading through each transcript to gain familiarization. At this point, the researcher continued with the process of horizontalization, identifying nonrepetitive or nonoverlapping statements within the transcripts (Hays & Singh, 2012). The researcher then conducted first and second-cycle coding on the data, identifying any common words, phrases, or ideas from the transcripts.

The next consideration in Moustaka's (1994) modification of the Stevick-Colaizzi-Keen method is to create textural descriptions. According to Hays and Singh (2012), a textural description is a way to bring refined data into new categories as to explore the meaning of an experience. This was done in order to create themes. Themes are considered to be the outcomes of coding, not things that are coded themselves (Saldana, 2015). Once all themes were identified, this researcher moved to the last phase of data analysis, creating a structural description. A structural description is "identified by the researcher and/or team, identifying multiple potential meanings within the textural description, in addition to variations among these meanings" (Hays & Singh, 2012, p. 355). Throughout the data analysis, this researcher pulled quotations from the transcripts in order to reflect meaning and contribute to overall findings. Extracting these "significant statements" allowed for a clustering of themes and an ability of the researcher to elaborate, creating an overall written explanation of the lived experiences of the participants (Saldana, 2015).

Trustworthiness and Credibility

The concept of validity in qualitative research is explained by the truthfulness of the researcher's findings; thus considered the trustworthiness and/or credibility of a study (Hays & Singh, 2012). Aspects of validity and credibility are detailed in this section. The researcher explored ways to address trustworthiness prior to data analysis, and ways to maintain it throughout the study. Researcher reflexivity, strategies for trustworthiness, and the audit trail are all explored.

According to Bloomberg and Volpe (2019) the researcher's role in qualitative inquiry is as instrument. Therefore, it is important to acknowledge the impacts of the researcher on the research process, as well as the impact of the study on the researcher him/herself. It is further noted that in quantitative research this may be considered a limitation, whereas in qualitative work the insights into research reflexivity are considered assets to the research itself. Therefore, the continuous reflexivity by this researcher is paramount and will be constantly explored throughout the study.

Researcher Reflexivity

Researcher reflexivity is a cornerstone of credibility and trustworthiness in qualitative research (Hays & Singh, 2012). The researcher pays attention to reflexivity in order to gain a deeper understanding of one's own experiences and how it affects inquiry (Patton, 2015). Therefore, this researcher consistently engaged in self-reflection regarding reactions and interpretations from the emerging data—paying particular attention to positionality. Hays and Singh (2012) highlighted Roger's conditions to researcher reflexivity as the ability to process one's thoughts and feelings regarding the research topic, as well as one's expectations from participants. This was continuously explored through this researcher's self-reflection due to professional work in the subject area and connection with the material. By focusing on the significance of reflexivity, this researcher engaged in journaling and field notes to document aspects of the research process during data collection. This was also continued during data analysis to include memos, in order to determine potential effects on/from this researcher regarding the phenomenon being studied.

The continuous process of reflexivity helped to identify any potential biases. Ultimately, the goal was to enhance the process of setting aside this researcher's own experiences and judgments; fully allowing participants to tell their stories. A focus on the potential threats to validity within the research design was combated by exploring the goals, conceptual framework, research questions, researcher role and methods with members of the researcher team (Hays & Singh, 2012). This researcher utilized a reflexivity statement as a form of bracketing.

Reflexivity Statement

The researcher of the proposed study identifies as a 30-year-old White cisgender female working toward a doctoral degree in counselor education and supervision. This researcher has been involved in counseling graduate studies (both master's and doctoral) since 2013, maintaining a mostly full-time course load. In addition to academic endeavors, this researcher is also a full-time Certified Child Life Specialist in a hospital setting and a part-time licensed clinical counselor/certified grief counselor in a private practice. The researcher teaches one adjunct course for a university titled, "Hospital Child Life."

The topics of death, grief, and bereavement are considered passions of the researcher. A combination of personal and professional experiences led to this as a research interest area. Personally, this researcher experienced her first death at the age of seventeen with the unexpected loss of her paternal grandfather. At the age of 22, the researcher experienced another unexpected death, that of her paternal grandmother. At the time, this researcher found it was difficult to talk about death with family or friends. The researcher observed both hesitation in herself to bring the topic up, in order to avoid making other family members sad, as well as observed a lack of conversation around death from her family. This researcher recalls attending funerals in her youth and aside from the overall presence of sadness, she most noticeably observed how people, especially her father, attempted to suppress emotions. These realizations became more aware to the researcher over time through age, education, and experiences.

This researcher's academic journey began with an undergraduate degree in Human Development and Family Studies with an emphasis in child development in 2012. She always had a passion for working with children and families, and a particular interest in the medical environment. Therefore, the researcher pursued a career as a child life specialist. As a child life specialist, one works with children, teens, young adults and their families who are sick, injured, have acute/chronic conditions, dying, or have died. Prior to obtaining a full-time job as a Certified Child Life Specialist in a children's hospital, this researcher had to complete a 480-

hour internship. The second day of this researcher's internship was the first encounter with a patient death—that of child. The researcher watched the interactions between her clinical supervisor and members of the family. The child's death was a traumatic and unexpected.

A few days later, this researcher and her supervisor went to the funeral home to complete hand molds for that child. Hand molds are considered one of the aspects of legacy building and memory-making that child life specialists offer. It was during this encounter at the funeral home that the researcher inquired, "How do people do this?" For in the researcher's mind, the ability to sit with a family during the most devastating moment in their life could not be met without an emotional response. The researcher wondered how professionals may be so stoic, and because of this researcher's internal emotional response, if this may be the right field. The researcher's supervisor then said it was not about "*not* feeling." Instead, it was more important to learn how one's emotions come into the room. The supervisor further explained that emotions are human nature and can of be of benefit—as the family recognizes that we as professionals are connected to them and their experience. However, she cautioned that professionals also have to be aware of when it becomes about their *own* grief. At this point, one needs to step out and explore what may be behind those feelings.

Through this interaction this researcher was able to work through difficult situations with supervision and support. Yet, once this researcher graduated and became a full-time Certified Child Life Specialist, she was struck by seeing the continuation of staff working with grief and loss and the lack of preparation and support. Thus, this researcher, and other members of the child life team often became sounding boards for not only each other, but for other medical staff who were experiencing the loss of a patient. The researcher identified a gap in education and support for professionals not only entering the child life field, but for nurses, doctors, and counselors as well. The research recalls that as a new professional, she felt a lack of preparedness to walk into end-of-life situations or explain death having never completed a course or training on the *specific* subject of death. Perhaps, now looking back, aspects of imposter syndrome were also present due to the emotional intensity that surrounded these situations. The assumption was made that knowledge would come through onsite training and experience. However, this researcher sought to learn more due to her passion and experience. Upon joining a counseling master's program, the researcher hoped to get more insight in working with death, dying, and bereavement; however, as noted earlier, it was not a part of the standard curriculum. In fact, this researcher only had one lecture as a part of a trauma class that covered aspects of grief and loss.

Furthermore, due to this researcher's professional experiences, whenever there were instances of death (loss of a student, family member, clinical case) this researcher was often consulted by her counseling peers. The researcher realized the impact of grief and loss, and the greater impacts of not making it a standard part of education for those in helping professions, particularly counseling. It is in counseling that clinicians sit with the most significant moments of a person's life, so why not talk about something so universal as death, loss, and grief? Therefore, through continued training and education, this researcher has made grief, loss, and bereavement (especially when working with children/teens) a specialty area—including creating of a study abroad course in the summer of 2019 for master's and doctoral counseling students in the area of child bereavement. Of note, the researcher enjoys working with children and families during these critical times and considers it a privilege.

Over time, this researcher has continued to get consulted regarding issues of grief and loss from school counselors, clinical counselors, child life specialists, doctors, and peers. It is the assumption of this researcher that issues of death and bereavement are still considered taboo and feel uncomfortable to discuss. Additionally, based on literature, and personal and professional experiences, this researcher has seen that individuals often feel uncomfortable with issues surrounding death, especially as they relate to children. Recently, one colleague who has been in the counseling field for over ten years stated that she felt ill-prepared to work with the population and would feel more comfortable referring issues of grief out to more specialized individuals. Yet, training and education are not widely offered or prioritized in this area.

Ultimately, the researcher's underlying assumptions for this research project are that topics of grief and bereavement are often ignored as a specialty area in counseling and are not commonly talked about, particularly in the United States. This researcher understands that the demands of accreditation and credit requirements in professional programs may not allow for the addition of specific electives; however, she also considers it a detriment to not include coursework in this area. Additionally, the researcher recognizes that individuals who are experiencing grief and loss may not need additional intervention; however, believes that professionals working in all areas (schools, clinical and hospital settings) should be familiar with grief, including that of a non-death loss.

The researcher understands and recognizes the personal assumptions presented within this statement. Furthermore, she understands and respects that these are personal biases and may not be shared by others. The researcher also recognizes the significance of her insider and outsider role in the study noting that grief is a part of her daily work and therefore a part of her livelihood. The researcher will continuously be aware of these personal assumptions, and refrain from bringing them into the study in an attempt to reduce researcher bias throughout the research process.

Ultimately, this researcher is interested in the potential insights from this study regarding grief work. As a clinician, supervisor, and future counselor educator, this researcher hopes to gain deeper insights into the lived experiences and preparation of child bereavement professionals. The researcher's motivation for conducting this study is to gain awareness as to the experiences of those working with death and dying every day in children's hospices. Furthermore, the researcher is interested in how these insights may impact students, members of society, professionals, and programming.

Strategies of Trustworthiness

Additional aspects of trustworthiness that were significant to this study included member checking, prolonged engagement, peer debriefing, and triangulation of investigators. Member checking was utilized as a part of the data collection process to clarify participants responses by asking probing or clarifying questions (Hays & Singh, 2012). This was particularly important due to the cultural considerations surrounding language and meaning of wording. This researcher continued to utilize this as a strategy of trustworthiness throughout data analysis.

Prolonged engagement was another important aspect of trustworthiness for the researcher(s). This strategy allowed an opportunity to build relationship with participants in their own settings to assist with exploration of the phenomenon being studied (Hays & Singh, 2012). The researchers considered this an integral part of the study and reasoning for why the interviews were conducted on site at each children's hospice in the United Kingdom. Prior to each interview, the researchers had an opportunity to take tours of the facilities and explore the environment with hospice staff. This allowed the researchers to not only build trust in the study, but also between themselves and the participants. This ultimately provided information about the setting, the goals of the hospice network and culture.

Lastly, peer debriefing and triangulation of investigators assisted with the trustworthiness of the study. This researcher frequently consulted with two doctoral colleagues in the NDSU Counselor Education department to assist with aspects of methodology and literature review. This strategy was continued utilized throughout data analysis as well. Triangulation of investigators speaks to the benefit of additional members of the research team when collecting data and/or analyzing findings (Hays & Singh, 2012). This researcher included two members of the research team when conducting interviews—Dr. Brenda Hall, a counselor educator at NDSU and Paula Abramson from Bereavement Training International in the U.K. The addition of the researchers' assistance with data collection was considered to strengthen the study and build confidence (Hays & Singh, 2012). The co-researchers also assisted with trustworthiness debriefing this researcher's findings at the completion of data analysis.

Audit Trail

According to Hays and Singh (2012), creating and maintaining an audit trail is important to a qualitative study. Audit trails provide a physical representation of aspects from the study related to data analysis. This researcher built the audit trail with certain aspects obtained through site visits, interviews, and tours while in the U.K. that would help explain analysis procedures. Items included in this researcher's audit trail included: timeline of research activities, correspondence between members of the research team, informed consent forms, field notes, photos, hospice brochures/information, reflexive journals, transcripts, and other items obtained throughout the trip to the United Kingdom.

Limitations

An important consideration for determining validity in a qualitative study is through the ability to recognize and describe potential limitations (Hays & Singh, 2012). The main limitations to the study focus on the recruitment of participants. All participants were recruited from children's hospices in the United Kingdom. Due to a utilization of a snowball sampling technique, there may also be limitations to the specific connections used for recruitment; not allowing for a more random sampling procedure. Another limitation included the data collection timeframe. Due to the researchers traveling to the United Kingdom, a shorter timeframe was used to conduct interviews. Additionally, due to three different members of the research team conducting semi-structured interviews, a potential limitation could include leading questions based on emerging thoughts from the researcher(s) during data collection. Despite these limitations, the researcher believes the post-study benefits outweigh the limitations.

Summary

The researcher utilized a phenomenological research design to explore the lived experiences of child bereavement workers in the United Kingdom. Data analysis was detailed and conducted through the use of Moustakas's (1994) modification of the Stevick-Colaizzi-Keen method. The methodological strategies utilized in this research study were explored. The researcher described an introduction to the study, research design, theoretical framework, participants, sampling, procedures, data analysis, trustworthiness/credibility and limitations. Results of the study are presented in chapter four.

CHAPTER FOUR: RESULTS

Chapter four presents the results of the study. The purpose of this study was to discover the feelings, experiences, and perceived levels of preparedness of bereavement support professionals working in children's hospices in the United Kingdom. This researcher sought to gain a better understanding of bereavement work through the experiences of individuals working in the areas of death and dying— specifically in children’s hospices. Chapter four outlines participant demographics and the results of the study.

Participants

A total of 15 participants took part in the study from six children’s hospices throughout the United Kingdom. A brief description of each participant and their hospice work is provided in Table 1 to provide context for the study. All participant names were replaced with pseudonyms, as well as all identifying information removed to ensure confidentiality. Participants all met the following inclusion criteria: (a) individuals were currently employed at a children’s hospice in the U.K., (b) the individual had a background in mental health, counseling, psychology or a related field, and (c) the individual’s role at the hospice involved providing support and/or enhanced emotional well-being for children, young people and families.

Demographic information was chosen based on significance to the study. Therefore, this researcher collected the following information congruent to the purpose of the study: length of time working in a hospice setting, educational background/area of expertise, and services offered within their role at the hospice. These areas of demographic information were important to the context of the study when looking at the participants lived experiences and perceived levels of preparedness working in the area of bereavement at children’s hospices. Commonalities across all participants included providing pre- and post-bereavement support directly within the hospice or in the community. One participant, Ruby, described pre- and post-bereavement services as creating a “package of support.” Tonya further expanded on hospice work in this way:

> We provide that continuation where other services may step in and out and may drop away if a child dies. We are supposed to be that continuation after the child dies as well. We do everything. We are jacks-of-all-trades, master-of-none, and it’s a lot of emotional support, practical support as well while the child is alive, just helping them navigate the complicated world of health and social care…finding out resources, listening, just being a sounding board for families and that pretty much continues during the bereavement period as well. Anything that doesn’t fit into any of the other boxes here, like the clinical care— there’s direct therapy work, the sibling work, comes our way and we will see what we can do with it.

The operational definitions of pre- and post-bereavement care are further defined to assist with clarity. Pre-bereavement work begins with hospice staff meeting with the family, conducting an assessment, educating about services and deciding on family needs. This could include a combination of medical care, psychosocial care (emotional support, therapeutic activities, counseling services), respite care, practical tasks (completing necessary forms) and overall care coordination. Post-bereavement support included a variety of services depending on the needs of the family. Most participants stated that this service was typically offered for up to 3 years post-bereavement; however, many participants discussed flexibility in this timeline to meet family needs. Along with the continuation of pre-bereavement tasks mentioned above, post-bereavement care also included (but was not limited to): providing support in a family’s use of the bereavement suite, involvement in memorial/remembrance days, and post-bereavement therapy. Many participants described the bereavement suite as a temperature-controlled cold room designed to help preserve the body of a child for, on average, up to seven days. One participant, Harper, further explained the bereavement suite as an opportunity for families to say goodbye:

> … they're our Butterfly Suites, our bereavement suites, that children can come here for five days after they've died…sometimes it's a bit longer; and the families have family rooms so the families can come and stay. This will be their room where they can come and be separate from other people….It's sometimes for cultural, for spiritual reasons—other times just because they want the experience, or they want help to say goodbye, or to have the siblings to say goodbye…

Harper provided more detail on the purpose and function of the bereavement suite and the care provided from hospice services:

> …I think to be able to have that time, from what the families say, is… so important… they don't have to cook or do all these life things, they don't have to do the laundry, there's someone that can do all that, all they have to think about is saying goodbye…. If a child dies in a hospital, it [the body] stays in the hospital morgue until they go to funeral directors… and that's very different, because the rooms in here are made out really nicely, and we always get a banner of their name; at night there's star projectors, and there's always music playing and it's just, it's just really peaceful. It must be so much nicer to see your child like that then to go into a morgue and have the body you know, in a bag; that must be just horrendous. So, I think it's that, it's that interim period between "my child's dying," "my child's dead and gone," and you have…this gentle five-ish days where you're processing everything. I can see the difference. I can see it kind of happening in parent's eyes and in sibling's eyes and thinking "what on earth do we do

> now?" and yeah…it's a really important part of the service that we offer, bereavement suites I think.

Bereavement suites were mentioned as a common service offered among participants. Further demographic information related to each participant, and bereavement services offered, is presented in Table 1.

Table 1

Demographic Information

Participant Name	Years in Hospice	Education/Background	Services Offered
June	6 months	Counseling	Therapy & Post-Bereavement Services
Parker	>20 years	Counseling	Adult & Children's Services- including community services
Mary	2.5 years	Level 3 Counselor (only use skills; cannot independently practice)	Pre- and post-bereavement work
Harper	8 years	Master's in Music Therapy	Individual & Group Sessions/ Pre- & Post Bereavement Support
Olivia	16 years	Social Work	Sibling Work/Pre-Post Bereavement Support
Lily	7 years	Child Development and nursing skill training	Pre- and Post- Bereavement Support; Management
Ella	4 years	Master's in Music Therapy	Adult & Children's Services
Tonya	4 years	Social Work	Family Support/ Pre- & Post Bereavement Care
Patty	6 months	Master's in Child Development; Degree in Psychology	Family Support/ Pre- & Post Bereavement Care
Liza	16 years	Play Therapy	Individual & Group Pre-Post Bereavement Care; Conduct Trainings
Brenda	11 years	Counseling & Family Therapy	Family Support/ Pre- & Post Bereavement Care; Staff Training
Paula	10 years	Counseling	Bereaved Parents & Children Pre-/Post Bereavement Care
Ruby	3 years	Early Childhood Studies	Family Support/ Pre- & Post Bereavement Care
Elizabeth	<4 months	Social Work	Family Support/ Pre- & Post Bereavement Care
Shirley	12 years	Counseling/Supervision	Individual & Group Sessions/ Pre- & Post Bereavement Support

Note. Demographic information for bereavement support professionals per children's hospice.

The participant and hospice demographic section was utilized to give context to the study results. The findings of the study are presented in the following sections.

Findings

The research question for this study was, "What are the experiences and perceived levels of preparedness of bereavement professionals' working with bereaved children, families, and young people?" Further objectives outlined in the study were as follows:

1. Bereavement support professionals' perceptions of their work on both a professional and personal level.
2. Specific training and other contributory factors that bereavement support professionals feel most important and useful in their work.
3. Content and practices of how counselor educators and supervisors prepare students to address the effects of grief and loss as they relate to children, young people, and the wider family system.
4. Bereavement professionals training experiences related to issues of diversity and cultural differences.

Guided by the research question and objectives of the study, this researcher analyzed qualitative data from 15 semi-structured interviews using Moustaka's (1994) modification of the Stevick-Colaizzi-Keen method. An existential theoretical framework was also utilized throughout data analysis. A total of six themes with various subthemes were identified. The themes and subsequent subthemes are listed below.

Themes and Subthemes

- *Foundation of Hospice Is Holistic*
    - Subtheme: Bereavement Professionals Provide Holistic Care Through Authentic Presence
    - Subtheme: Hospice Work Requires Honoring Choice and Flexibility for Families
    - Subtheme: Hospice Allows for Greater Flexibility for the Practitioner
- *Bereavement Work Entails a Unique Developmental Process*
    - Subtheme: A Calling to the Work
    - Subtheme: Developing a New Relationship with Death
    - Subtheme: Practitioners Develop a Concern for "Getting It Right"
- *Nature of the Work Requires Additional Support and Supervision*
    - Subtheme: Bereavement Preparation is Inconsistent
    - Subtheme: Qualification Focus Emphasizes Emotional Intensity of the Work
- *Perceptions of Death and Disabilities Matter*
- *Death Work Allows for a Greater Focus on Life*
- *Children Present with Unique Perceptions and Needs Related to Grief and Bereavement*
    - Subtheme: Developmental Considerations
    - Subtheme: Power of Words

Direct participant quotes are included below to capture the essence of bereavement professionals lived experiences and perceived levels of preparation.

Theme 1: Foundation of Hospice is Holistic

Several participants discussed the holistic nature of hospice work due to its family-centered objectives working with individuals with life-limiting conditions or those at end-of-life.

Participants spoke to a unique model of care utilizing a holistic lens to meet community, physical, social/emotional, cultural, and spiritual care needs. When asked what led her to this work, Ella shared that she had been waiting for an opportunity to work in a children's hospice. In her eyes, "a hospice was still a place where the person was the heart of the care and where care was provided in a more holistic way." She further noted that compared to the "therapeutic sector" the focus was less on numbers and more on the patient and family needs. Many participants also focused on this, including the atmosphere of the hospice and the variety of bereavement services available to families.

A part of holistic care included attending to community, cultural, and spiritual needs. Most participants talked about how their hospices provided community support or were community focused. This included going into patient homes, engaging the community in education on disability or bereavement, or conducting trainings. Patty emphasized the importance of this work by stating, the "hospice has value, and is a valuable thing for communities." She further reported the hospice is a place where bereaved families, or those experiencing a child with illness can come and "just be." Through this focus, hospice staff worked to bring about a sense of normalcy regarding topics such as death and disability.

Cultural considerations were prevalent throughout participant interviews. Most participants spoke to the unique model of care for families and considered the focus on culture and spiritual needs to be a major component of well-rounded care for families. Study participants gave numerous examples of the ways in which cultural and spiritual needs were included as a foundation of hospice care.

Mary shared an example of how important it was to pay attention to each family's unique needs and the way culture and spiritual needs impacted one's grieving process:

> … for example, our Muslim community, once you kind of have that 40 days of mourning, there's an expectation that mothers are meant to just then get on with things. So, I'm thinking of two particular moms in my mind, they will tend not to talk to members of their community, so they actually appreciate a visit because they can be themselves, and they can let it all out. So… we're trying to kind of think of ways, like creative ways, where we can accommodate them so they can come out and meet the wider community of where they can be themselves. I think, at the moment, it's the Muslim communities that I'm quite aware that the moms, they've got a lot of rituals, even around the burial, so mothers are not even meant to be graveside— they're meant to stay quite a distance away, they're not supposed to cry…it's quite interesting, it's quite difficult to observe…, it's quite difficult to actually be a part of that, but I have noticed as the times have gone on, I know that as the generations are moving on they are trying to kind of change that, and I think the reason they're trying to recognize that actually, what harm is there if a mom grieves for her child? So, it's just breaking those old-fashioned cultural rituals.

Mary spoke to the importance of recognizing one's role in bereavement support and honoring cultural differences. It was noted that accommodating for cultural needs in bereavement work is important; however, can present challenges as well. Ruby further explained the impact of cultural/spiritual accommodations and the connection to community support in this way:

> We had a family who were from Zimbabwe and…their child died quite suddenly; they knew it was coming, but…they didn't know it was happening imminently, but it did; so…we are community-based as well. We went into the home and the family were able to

> carry out their, they did like a religious dance, and the family would come around, and they all carried out their religious practice— and mom had approached me afterward and said, "I know this is not something that the hospital would have been able to allow."

Many participants spoke to the significance of meeting families where they were through individualized support and by creating moments during bereavement that were true to family values. A common element among participants was how this model differed from the hospital environment, a shift from where cure ends, and care begins. Parker explained this as a difference between the medical model (curative/treatment mindset) and the hospice perspective:

> I think there's a lack of understanding and I think what's happening these days is the hospitals are waiting longer and longer and longer to admit that somebody might be approaching end of life. So, in my book what they are doing is they're often dangling carrots saying "no, no, no, there will be another treatment, we'll find another treatment, we'll push, we'll push, we'll push," and then somebody is very clearly end of life and then they say, "now we'll refer you to [this hospice]." So, we are occasionally getting people brought over in an ambulance who are dying there and in the last… 24 hours of life, and that just feels as if it's happening more and more now…so, I think fewer people feel like they are having that conversation about "let's ready you for the end, let's look at the last, say, two years." That's now been reduced to "let's look at the last two weeks of your life and get you sent over to that place [hospice]" so it's really difficult.

Bereavement Professionals Provide Holistic Care Through Authentic Presence. A subtheme that emerged within the theme of the, *Foundation of Hospice is Holistic,* related to bereavement professionals' presence. Participants reported that a major element of care included a willingness to be present and show up authentically with families. Ella shared "one of the major elements of any bereavement support is just being there and witnessing, rather than wanting to change or wanting to make it better…" while Brenda also noted that the work entails a sense of "being." Elizabeth reiterated this when asked about aspects of preparation for bereavement work. She stated that there are qualities bereavement workers possess and provide through authentic connection and presence, including to "withstand sometimes as well, to bear to sit with someone's pain I think can be really hard. Not wanting to fill those silences and not…you know, resisting that urge to "do" something, to help to fix or to remedy." The understanding that there was not a "fix" to bereavement support was prevalent in the experiences of bereavement workers, and pointed to the support of mutual empathy, authentic presence, and connection in holistic care. June further expressed the power of connection in reducing fear and enhancing care:

> It's such a vulnerable point in people's lives and I think it is the point where if you enter someone's life you really are being privileged with an incredible amount of trust um, and I think it's probably the point in everybody's life where we're really seeking empathy from other people; I think that's what I enjoy about it most is that connection that you are able to make with people in those sort of very vulnerable moments and it isn't, it definitely is awful, but sometimes it's not as scary when it's shared and that's what I think I've found with most people that I've worked with is that the fear element really reduces when they're in contact with someone else, and I think that's why I'm so privileged to be able to do that with people in those moments.

Hospice Work Requires Honoring Choice and Flexibility for Families. The significance of choice and flexibility emerged as another subtheme. Participants described the importance of these concepts as a way for families to be active participants in their own care.

Participants stated that even though death may be viewed as an ending, most participants viewed it as an opportunity. Ella highlighted this, sharing that because every person is going to die someday, "…there lies a, a profound opportunity in looking at death and dying…." Participants further reported that they focused on creating opportunities by honoring choice and providing flexibility for families when it seemed like there was none. Tonya summarized it in this way:

> Death is so personal and so individual that for me, or the organization, or the law, to dictate what should happen and when— it's, I mean, you're not going to get a one size fits all anyway. Having choice…gives families a little bit more control at a time where they have no control.

Tonya continued to express thoughts on flexibility and choice in regard to the bereavement suites and services provided:

> Here it allows families a bit more flexibility as well. So, there are open times in funeral homes where you can go and sit with the body, there are restricted times in hospital mortuaries whereas here it's really not restricted. Families can go in and out as they please to spend time with their child. So, it's choice, yeah, giving families the option… I know just, it was about this time last year, one of the families I'd been working with um, a 12-year-old boy died, and it was… for mum, … just obviously, the worst experience of her life… so she went to another local hospice…used their cold room and bereavement suite for a week, and she could not express how beneficial it was just, because she couldn't let go. She needed that time and she has since said, "you know, I couldn't…just walked away when he died in hospital" and at the end she needed that week to get her head round that her son had died, and she said it was really nice being in the hospice environment even when she went off to sleep, knowing that there were other nurses or

> carers who would just pop in and change the CD that was playing in the background—that her child wasn't on his own. I don't imagine she left him for long, but she said you know there were times when she was told "just go and sleep, we'll look after him," and she really appreciated that. And I'm not sure you get that in a hospital morgue or funeral home; whereas here,…we will have people on-site that can just pop in, change the CD, just talk. So, I think that's quite comforting, certainly from her, what she reported.

Participants described choice and flexibility as a powerful tool in working with disability and death. They noted that allowing families opportunities to say goodbye, on their terms, assisted with the grieving process and gave back a sense of control. Participants voiced that bringing choice back into bereavement and end-of-life work allowed for new perspective, understanding, and awareness. Ruby shared that it felt like a simple, yet underused concept. She compared end-of-life support to when children are born, noting a difference in support and instruction:

> I just feel that when a child is born there is a big… appreciation around new life and how important that is, and instructions to the family. And I think there's a lot of choice through kind of you know, birthing plans, for example the child entering the world… I do feel like when a child dies, families need to feel that they've got a lot of choices; and I think it makes it easier for them to accept. It's never going to be easy for them to accept the fact that their child has died, because there's a lot of questions that they're going to have, but I feel as much choice and guidance and support that they are given, the easier it is for them.

Olivia furthered reported the sense of holistic care through flexibility and choice by stating, "… it's not 'one slice fits all,' it never can be, we're individuals and we couldn't be more individual in our lives, and in the way we handle end-of-life, and what our needs are."

Hospice Allows for Greater Flexibility for the Practitioner. The third subtheme emerged with a focus on flexibility provided by bereavement professionals. Participants spoke to an ability to adjust services in order to meet a family's needs through length of time provided, amount of time spent in sessions, and variation of services provided. Practitioners spoke to an appreciation for clinical judgment and personal decision-making ability with each family. Participants noted that this was different than working in a traditional system environment. Brenda shared insight on the importance of having flexibility as a practitioner:

> …the families moving on and away from hospice…still having access to support. So, we would never close the door, you know, if somebody ran out, and they do sometimes…but maybe six, seven years along, needing that support…we might have some time to talk to them. People come into the hospice many years on, on anniversaries…, that kind of thing. I think all those things are really important that they can access that service for however long they might need it because of it being so individual. So that's the sort of thing I would say in terms of the bereavement support here and what I think has worked for us.

Ella further explained the difference in bereavement professionals' flexibility in practice by comparing it to a system that has productivity requirements. She discussed an individualized approached to care within hospice work that focused on quality instead of quantity:

> You can't say "ok, I've seen 15 people a day" but the quality of what you provided was actually not what they might have needed on their journey. So, a hospice setting for me was still a place where the focus on the human being and the person was there and um, it was kind of confirmed over the years of me working here…. I have the liberty of delivering sessions for longer than a ten-week slot… I have my own clinical decision-

> making capacity to say I would like to continue with this child for this and this reason, um, which in other places is not necessarily possible. You get a 12-week block and that's it, and then you have to be out of the system. …that's one of the things that I really appreciate about this work.

Theme 2: Bereavement Work Entails a Unique Developmental Process

Throughout the interviews, participants spoke to an experience of developmental growth in relation to their bereavement work. The process included changes in one's view about death, personal and professional growth, and experiential learning on-the-job. Many participants discussed lessons they learned through the work both personally and professionally. June shared the most important lesson she learned in her role was "gratitude," however, she also discussed the significance of learning comfort through discomfort— particularly as it related to sitting with uncomfortable conversations. She went on to share that although the experiences may have been uncomfortable, they assisted in growth for both herself and her families. Ella reported how she learned to lean into courage and not be afraid of suffering when it came to bereavement work:

> Another thing I had to, over time… learn is more courage… I think that's in general just the, as a therapist, in this kind of profession to have the courage to really go into what is presented to you, into the depth of pain, of anger, of tears, of sadness, whatever, you know? To really go there with someone takes a lot of courage.

Ella further reported gaining new insight and meaning through her work. She identified that growth occurred through her role, and she was able to identify new connections and awareness:

> …as you mature in this job a little bit more you realize the connections to your own personal life, you know, things that had happened in your personal life that had brought you onto the track of a therapeutic profession to understand more about what you have

> experienced these kinds of things and how your experiences might be valuable for people… who go through similar experiences. And by that, turning your own pain or experiences of suffering into something precious for other people.

Shirley also talked about her developmental process as a new counselor. She described building confidence by being her own teacher and learning through experiences:

> I think that is the part of when you're counseling… when you're a new counselor… you don't know everything, and when I look back, maybe about even eight years ago I probably work so differently to how I do now, and I think it's confidence. I think its life experiences; I think it's knowledge, reading, research, courses, it all, you know, you can't stop absorbing it. And I do think it's also, I think you could probably read all the books, um, as much as you can about bereavement, but I just think nothing ever really prepares you for when you're actually working with people and you come into this stuff…

Mary reported that due to the nature of the work, the best way to learn was by jumping in. She also described recognizing the gravity of bereavement work:

> I don't think anything really prepares you for this role until you're actually doing it…I started in the summer and within about a month into the job my first, very first young person died…then it really hits you, "this is what I do for a living."

Participants discussed the emotional impact of bereavement work with multiple participants stating how bereavement work wasn't for everyone. However, most participants also expressed a feeling of being "called to the work."

A Calling to the Work. The first subtheme to emerge was participants expressed feelings of being called to bereavement work. Although most participants recognized the emotional intensity and demands of the job, all participants reported feeling passion for the work, a sense of gratitude, or acknowledging a privilege in working with families during a vulnerable point in one’s life. Mary shared that she felt “honored that a family has allowed me into their lives; that’s huge, to actually walk alongside them and let me into some really private and intimate moments.” One participant, Paula, described securing her job at a children’s hospice like the “…icing on the cake.” Other participants described accidentally finding the work but feeling that it was meant-to-be, as Tonya reported being surprised by a calling to work in bereavement. She noted that she found “satisfaction” and fulfillment from the work in ways she hadn’t realized:

> I never saw myself as a bereavement worker; that never really crossed my mind until I found myself here… the bereavement side of things was not what motivated me to apply here, um, but it certainly interested me enough. And then since starting here, being much more immersed in the field of grief and loss…I found a job that I actually, really, it’s the longest job I’ve been in. I’ve never stayed in a job for longer than four years, or at the very least I’ve been browsing, looking. So, yeah, there’s obviously something about this role that is working for me, ticking boxes that others hadn’t. The job satisfaction is, it’s a bit perverse, you know, you’re getting satisfaction at a time when other people are at probably the worst moments of their life…it’s so cheesy, but it really is a privilege that people are letting you in.

Additionally, Harper stated that bereavement care wasn’t necessary a starting goal either. However, when asked about her journey to hospice, she reported it was a safe place to land:

> It took me a while to land myself here, so I tried everything…I worked in a couple of schools, and in dementia care, with adults with learning disabilities as well… Yeah, I

> wanted to see where I was supposed to be. I never would have thought I was supposed to be here, but clearly, I was.

Participants also reported a sense of connection and job satisfaction within their bereavement work. Lily reported having a sense of belonging immediately during her interview:

> I think when I first came in… it's weird because I just knew that I wanted to work here… it was just something that when I came here it was like, I don't know, it just felt like it was a good place. It's not… a sad place, there's times when yeah, there's sadness going on because families are going through sadness, but, on a day-to-day it's not a sad place, it's about you know, giving families a nice time when they're here. A positive time; they've got so much going on in their everyday lives, they don't want to come to another sad place where somebody doesn't want to say "hello" or chat with them… when I just came here it was just, a place that felt like it was going to be a right place to work really.

Most participants described being called to bereavement support but found their path to the children's hospice in a variety of ways. Participants discovered hospice work through personal experiences, connections from individuals who had utilized hospice services, or gaining experience/exposure to the environment based on one's career path. Additionally, most participants reported a positive outlook on their work even with the hardships of working with the dying and bereaved.

Developing a New Relationship with Death. Another subtheme within unique developmental needs was centered on participants developing a new relationship with death. Most participants reported increased or improved personal death awareness through their work. Furthermore, participants shared the way they identified with death had changed, and that feelings around the topic were also coming up in their personal lives due to the nature of their work. One participant, Ella, reported how her relationship with death changed after starting her role at the hospice:

> The feeling before coming here was anxiety…what would this be like, “oh my God, what did I get myself into?”…We all have ideas about a hospice, you know, what happens in a hospice and what kind of people are there and I think in general our idea is a place of dying and death…until you take that plunge, that leap of faith, and over the first few months or so you realize that actually, um, this is a place of life more so than death, or maybe because it’s connected with death it’s such a place of life… in a way the question might be, you know, whether this awareness of death brings us much closer to focusing so intensely on life and what it means.

The connection between life and death was prevalent in most participant interviews. The expectations related to what participants thought grief work entailed, compared to their experience, also provided insight into their development with the concept of death. Parker discussed the way in which expectations of grief and bereavement work changed upon securing a job at the children’s hospice:

> …it’s been much more, I guess open, than I expected that it would be, the work is much more open, so I thought bereavement would be very narrow and fixed and about this one subject—grief and loss bereavement, and actually it’s about so much more than that of course it is, and always is in counseling, because it’s about relationships and hopes, and fears, and dreams, and all… so much more than just focusing on that particular loss.

Participants also discussed their openness to death constructs throughout the interviews. June discussed a willingness to engage in conversations around death in her personal life, yet recognized a hesitancy from those not working in the field to discuss topics related to death:

> I think because I’m that way in my practice, I’m that way in my personal life as well which none of those people have opted to be a part of that bereavement work and none of them have said you know that they want to engage with the reality of sort of life and death in that way so I think that can be quite sticky sometimes…I think there is definitely a stigma that death is always something that is awful, I don’t agree quite a lot of the time. I think death is a release, I think it can be a release for a lot of families, and for a lot of children, and I think for the general public. That is something that is really difficult to grasp our heads around until you start watching someone else’ issues a little bit, or you’ve been able to empathize with someone else’s position for a little while.

Ruby talked about the increased self-awareness toward her personal and professional experiences with death and her ability to grow within her position and identify boundaries:

> Yeah, so I think it’s me becoming more self-aware and allowing myself to take an hour out after say for example a funeral or being with a family when a child has died, and learning what works for me and how I’m going to be able to kind of cope through that time. I have colleagues that do struggle with it and I think I have as well, but I think you grow in a position, don’t you? And I feel that I am growing and I’m learning how to deal with things.

Practitioners Develop Concern for “Getting it Right.” The third subtheme is connected to the experience of getting death work “right.” Participants discussed the importance of death work in that there are no opportunities for second chances. Participants conveyed a sense of urgency in their work to meet the needs of families. Due to the finality of death, the opportunity to change support strategies or rephrase information is limited. One of the participants, Harper, discussed the significance of wanting to get death work right for the families:

> I think an openness, a willingness to be questioning and find out what those needs are, I think it's really important to bereavement care because you can't get it wrong, you mustn't get it wrong, because it's so important to these families' mental health going forward and their processing of their grief that it's done right in those early stages…I guess it's around training as well and it's that each of these children only die once, so if you get it wrong, and I don't know what "wrong" would be… but it, it's the impact that might have, and it's something that I can't do over, I can't do it again, because the child's not going to die again and get it right next time, so it, yeah, it's that sense of… just wanting to make things that I can control better.…We all work in this industry because we want to help, and if we get things wrong, and don't do that, then it's the opposite of why we wanted to be here and that doesn't quite sit right.

Liza additionally talked about "getting it right" through the lens of cultural and spiritual implications:

> This is from my experience, but I think generally in the UK they are quite accommodating to other beliefs, other cultures…you die once, and you have to make it right, and that's why the people, the staff, wants to accommodate the other people's beliefs and the cultural things.

Ruby further articulated a sense of urgency in the work, and the need to "get it right" by addressing regrets. Ruby clarified a difference between regrets and what-ifs stating, "there's always going to be regrets, there's always going to be "what if's," but there's only one, you've only got one chance to support because this child only dies once, so we need to make sure that we get it right." Participants referred to this feeling as a sense of urgency and purpose…speaking to an additional pressure due to the finality of death.

Theme 3: Nature of the Work Requires Additional Support and Supervision

The third theme identifies the significance of support and supervision in bereavement work. All participants identified the support of colleagues and impact of consistent supervision, regardless of clinical licensure status, provided within the hospice environment. Bereavement professionals identified this as a staple to their work and work/life balance. Harper talked about clinical supervision as a necessary part of her clinical practice:

> I mean, the most important for me is clinical supervision and I do that every two weeks and I just don't think I've ever missed it. I think without clinical supervision, or the opportunity to just vent with somebody, then I would have left this business a long time ago, um, so that's very, that's the most important thing.

Harper also mentioned the importance of using "black humor" to process and cope with traumatic events. She explained that having support from colleagues, knowing that one can laugh and joke about death, is extremely helpful to overall wellness and staff satisfaction. Lily also identified fellow staff members as a consistent form of support as well as opportunities to debrief tough cases. She recognized members of her team as essential to her workday due to the nature of grief and bereavement work. Lily explained the significance of her colleagues and ability to debrief when needed:

> There's been a few circumstances where we've had quite a heavy emotional day but you know, we've all hugged and we've all thanked each other for the help we've had off of each other during that day— it's kind of like a mini-debrief I suppose in a way; at the end

> of a shift you know, "thank you for your help today" and "thank you for"…so that's kind of I think, is also a way of you know, keeping that in a pocket somewhere.

Ella also talked about the significance of the colleague relationship and that bereavement workers "tend to have closer relationships with colleagues because it's such an intense job." Brenda also spoke to her sources of support, strategies for self-care, and boundaries in the workplace and at home:

> I would say the main source of support for me is my therapy team and my counseling colleagues over here, as well obviously… my external supervision. For me personally, what's really important for me is work is work, home is home… I think that is why I like this type of work, working for an organization, in a team where I know people will be supportive, there's an element of a bereaved family can ring up at 3:00 in the morning and speak to somebody because the in-house team are here, so you don't, I don't have to think about families when I'm not here… so that in terms of support and how to survive the work that's really key for me.

Olivia also reiterated the importance of checking in on staff and working collaboratively:

> I keep reiterating whenever I'm working with staff…we have to check-in with ourselves at all times because…what are we doing this for? And, to find that separation, it's a lifelong process really and we need to keep on reflecting.

Bereavement Preparation is Inconsistent. A subtheme that emerged regarding support and supervision was that bereavement preparation was inconsistent. Participants reported a variety of educational/training backgrounds coming into the work, but no consistent bereavement training or education among the group. Additionally, bereavement support professionals discussed some training opportunities available, most noticeably through the hospice, but a feeling that overall training is lacking or not readily available. Most bereavement professionals identified a desire for more training, to reduce the stigma on death and focus on professional dispositions in death work. Parker talked about the lack of experiences in training, including opportunities to train staff and students:

> Absolutely, I was horrified in my own training at how little we talked about death, how little we talked about serious ill health, how little we talked about disability, so those are the three areas that I think we focus much more on here, and of course bereavement, so, after a death. So, that's the real focus and we get, as I say, people who've gone through their first year of training and when we do the training on bereavement they are pretty awestruck actually because they have not heard any of these theories, they haven't explored their own feelings about death and dying as well, many of them haven't explored their own feelings about losses they've experienced, and it's quite shocking really given that these are these are counselors that are going to face this all of the time in their work.

Parker continued to discuss the importance of training and ways the hospice provides training for their own staff and members of the community. Parker noted that individuals who do come to training often feel overwhelmed from the information and it becomes a challenge to take in information while trying to simultaneously explore one's own feelings of death.

June talked about her experiences seeking out more information related to culture and theory, and the lack of available information:

> Nine times out of ten really, when I'm discussing bereavement with someone they are going to be of a different cultural or religious background to me, and my understanding and my basis of my training so I've had to do quite a lot of work since to even out my

> knowledge base, and that's been a little more difficult than I anticipated it to be. I thought there would be more information available but there isn't…I wish I had a better idea of the cultural differences to do with bereavement… I have found that my practice had really been lacking in any knowledge of that those cultural differences in grief and it's actually on the job that I've had to do…the research, and be resource efficient in teaching myself, and finding people to teach me about cultural differences in grief and bereavement.

Shirley also discussed the importance of educating individuals on grief through an example with a client, recognizing that individuals need to have some foundational knowledge in normative grief responses to provide care:

> I think to have the knowledge of what they are expressing, so that you can educate them… One woman, she said, "I feel I need to see oh, someone else, a psychiatrist." I said, "why do you feel you need to see a psychiatrist?" "Because I just don't feel like how I used to feel, I just don't feel myself" and I said, "but you're not going to feel yourself because you've lost a child…" and she [the daughter] …was two year's old, died very quickly of a tumor… I said, "but tell me what you are experiencing" and she sort of went through her symptoms and I said, "this is grief, this is what grief is, you can't expect to go back and be the person that you were with those feelings, it's, this is a new you, this has to be, starts becoming a new norm of these feelings and you know, you can't say how long you're going to feel like this for, it's about time, it's about working through those feelings and expressing them" and I printed off some information about grief and symptoms and I said "go home, read this, see if there's anything you can relate to, if you feel that this is something you're still don't feel right for you then you know, we'll come

> back and we'll talk about it" but I think education is a huge part of grief work and knowing actually, because I think what you feel is so un-normal to you, and I think just educating them that this is ok.

Qualification Focus Emphasizes Emotional Intensity of the Work. The second subtheme of support and supervision is on emotional intensity of the work. Participants described necessary qualities and qualifications related to those providing bereavement support with a focus on personal death awareness, emotional wellness, and insight. Participants seemed to identify that qualifications needed for bereavement professionals required a deeper focus on the bereavement professional's dispositions (ability to hold emotional intensity of the work) rather than just theoretical/practical knowledge in grief work. Although bereavement support training was found to be inconsistent among participants, there appeared to be commonality in the desire for additional training needs addressing qualities of resiliency, integrity, and emotional self-awareness. Tonya shared that bereavement work is not a one-size-fits-all and individuals in the work need to have clear expectations and support:

> I don't think everyone can do it, but I think that being able to be boundary-ed, I really think should be well up there, much more than being a good listener…would be up there, but if you're a good listener but then get involved too much, I think you've got to have the boundaries for yourself as much as the families you are trying to help. The good listener, the non-judgmental, the kind of standard listening, but I think the non-judgmental bit really comes into play particularly when you are working with all sorts of beliefs, that aren't necessarily your own, and not making assumptions also. Learning to sit with the discomfort. If you can do that, and that again is about your own self-awareness.

June further explored the idea of integrity as a quality within bereavement work in order to cope with one's own feelings regarding highly emotional situations in bereavement work:

> I think it really comes down to integrity. I think that that quality of being able to be honest with yourself with what you can cope with, um, and how you will cope with those things in a healthy way is really important and I think the integrity that you show families in your empathizing and your communication is really important.

Other qualities identified from participants related to resilience, strength, and sensitivity. Harper explored the significance of resilience when working in bereavement due to a high stress environment. Additionally, Harper discussed the significance of working with those who have just experienced the death of a loved one:

> …resilience, I would say is a big one… and in resilience… I'm not talking about strength, because I don't think we should be "strong" I think we need to just be able to… make it through a session and sing, and play and talk while there is, you know, a dead baby there, um, without breaking down, because it's not going to help anybody if I'm just there crying. It won't be the end of the world if that, if I do, but it's not going to help anybody, um, so resilience in that respect…And then probably sensitivity as well, so they're kind of almost opposite strengths, aren't they? Resilience and sensitivity, because I have to be able to build these intimate therapeutic relationships, really quite quickly; especially if I'm working in the bereavement suite, in a matter of minutes with a family that I may never have met before, and really quickly I need to get to know who they are, what their needs are, what their therapeutic needs are, but what their spiritual needs are what their cultural needs are…

Ella also mentioned qualities related to resiliency and sensitivity as important pieces to the professional journey:

> I think we need this mix between sensitivity and resilience. Um, often people who are not kind of in touch with a setting like this or with work of this kind, I think there's often there's this common misperception that we're really tough as nails, and nothing shakes us and um, we just shake things off, it doesn't get to us, but that's obviously not true, um, and if you want to accompany people at such a delicate time in their life, you have to be sensitive to their needs, to what they communicate or what communicate quietly. So, the sensitivity to work with people on that journey is essential, but at the same time then you need the resilience to deal with it, and the coping strategies, you know, what do you do when things come too close or how do you manage your own self-care and your own well-being to be able to provide this for other people. So, um, yeah, I think these two words "sensitivity" and "resilience" are probably the main components I would say.

Theme 4: Perceptions of Death and Disabilities Matter

Participants identified a common theme related to perceptions of death and disabilities, that perceptions related to these two areas matter in hospice work. Participants indicated that these perceptions may affect a family's access to care and the way individuals make meaning of, engage with, and understand death and disability. Bereavement professionals talked about a variety of societal perceptions, including misconceptions, regarding death and bereavement work. Parker further addressed the societal fears surrounding death and facing one's mortality:

> I think there is, I do a lot of teaching on bereavement and I think there is a societal fear about death, we hide death terribly… we just hide death permanently I think, and I think it's very dangerous to the point that the patients that we talk to here that are facing their

> own deaths and their families can’t even discuss the fact that somebody is going to die, even when it’s staring them very firmly in the face, so I think there’s a societal issue that we need a massive culture shift before we can have a much more open dialogue about the fact that we are going to die and we need to make some preparations.

Ruby additionally shared that she had someone in her family with Down’s Syndrome, and growing up, she recalled recognizing a stigma around disability as well, that “death was accepted, but a disability wasn’t, it was a very taboo subject.”

Participants also reported receiving a range of responses from individuals regarding their profession. When asked about people’s perceptions of being a child bereavement worker, Olivia shared the following reactions:

> …people would say either “you’re a saint,” “you’ve got this reflected glory,” …“I couldn’t do it,” “I’m not strong enough,” “I’m not tough enough,” “I’m too soft,” or “you must be an angel,” and, people who work in this area are neither….I wasn’t then, I’m not now. We do it for our own satisfactions and to satisfy something; and we’re all, I believe in some ways, wounded healers— and I think that runs through the profession and runs through many caring professions.

Harper further explained death as something that individuals are often “scared of,” while also describing the importance of word choice when discussing death and the fear of the unknown:

> I think it’s not really spoken about very much…people are really scared of death and dying and the unknown…. people don’t talk, people hold it in, and I’ve seen people at funerals just, either in absolute floods of tears because they kept all in until there, or just still really stoic and you can see them holding it all in. And yeah, not many people say

> "death," or "dying." They don't say "they died..." it's "we lost them," or "they passed away," or "they passed over," "they passed on."

Participants noted the stigma of death may hold individuals back from fully embracing the opportunities within end-of-life support and conversations around death. Ruby stated that the misconceptions were prevalent in how individuals viewed her work as a bereavement support professional at the children's hospice:

> When I talk about what I do… I get very kind of concerned looks, or "oh, how do you do that?" "do you not cry all the time?" and I don't think they can fully understand because we don't just, we're not witnessing the child's death at the time, we're not just sitting with the death of the child. We're involved in a lot more aspects of the family as well. I do get… "how long are you going to be able to do that for?" and always kind of doubting how long someone could do my line of work.

Ruby talked about the impact of societal perceptions and how fear of death can have an impact on the awareness of hospice work. Harper further supported the concern regarding hospice stating, "there's so many people out there that we could be supporting that we're just not, because they're scared of the word 'hospice.'" Participants also highlight the fact that many individuals believe that children's hospices are a place where sick children go to die. Harper reported that before taking a role within hospice, she had similar beliefs about what a children's hospice was:

> I imagined it would be like this big Victorian building with rows and rows of sick, dying children and people walking around crying and moaning out in pain, that's how I thought it would be. It's really strange that I thought it would be that now, but it, I think it's really

> important to remember that a lot of people out there who have never been, probably think that too, because if I did, then surely, they would.

Theme 5: Death Work Allows for a Greater Focus on Life

Participants consistently described a greater focus on life through death work. Bereavement support professionals experienced situations related to suffering, disabilities, and death, yet maintained that hospices were a place of hope and healing. Through this focus on life, participants discovered a deeper awareness into their needs, while learning how to create and hold space for themselves. Bereavement care focuses on honoring one's life through end-of-life work. Harper further described the way her hospice focused on life by understanding that end-of-life care could allow for choice, creativity and fun:

> We always use the tagline "it's about life," and it is about life, it's about making the most of the time that we have, so it is a fun place, it's a really interactive place, it's a responsive place; each child who comes here whether it's for end-of-life care or for respite it, they get to do what they want to do…there's just constantly stuff going on, there's just fun to be had.

Patty shared that a part of the work was helping others rediscover how to live. Patty explored the significance of focusing on life as she described bereavement support services:

> I think adults' reaction to my job is a bit dramatic in my opinion because, they're like "well, your job is so sad," but it's not, because in the time…the child is known to us, we're doing and making sure that they have experiences and their family make nice memories with them. And so, when the time does come and that child does die, yes, the child has died, but they can say "my child lived the best life for them" and that's kind of how I see my job…

Many participants identified the importance of life as a way to honor the person, the family, and to provide choice. Similarly, Ella recognized a chance to make life a focus in her work and considered it part of a "self-preservation" in doing this work:

> …changing from the perspective on death to a perspective on life, I think that's the major change, which might also have to do with um, a self-preservation if you like; you know, if you come into your job and you know it's all about death, you're probably not going to do it for long.

Participants described a greater awareness into both professional and personal needs through the experience of doing the work. Participants identified a clear focus on boundaries for both work and home, as well as consistent self-care practices to assist with overall well-being. One participant, Harper, explained the significance of boundaries in her work as:

> … I explain the boundaries quite often as being an elastic band, so the boundary is always there, it just sometimes is a bit looser and sometimes needs to be a bit tighter, so yeah, the need to be responsive, to be flexible, but not to ever let go of that…

Paula also discussed boundaries and recognized the significance of holding space for herself repeating, "it is about self-care, this job has to be about self-care." Participants further discussed the significance of focusing on life and boundaries and how that also translated into their personal lives. June also described creating grounding opportunities and worked to enhance her mindfulness practices:

> …I really find that helps ground me and it helps me be very present in the time that I'm experiencing you know those feelings of gratitude—like to the point where I sat on the train and I think I've seen something lovely, or a nice interaction with between two different people or whatever, I will write it down wherever I'm sat; sometimes I find it

> easier to, especially if it's been a bit of a crap day to end the day by recapping it and trying to find those positive moments that happened throughout it. So that's really like my main self-care at the moment is being appreciative of what I have and being very aware of what it is that I have, and it's not all bad even when it's a really bad day.

Similarly, Ella discussed the importance of creating meaning in order to make sense of one's experiences both professionally and personally:

> I think we all need to make sense of what's happening to us in life and what we experience, what we go through, and I think one way of making meaning is to reverse that whole thing of… something painful, turning it into something positive…to turn those processes into expertise for someone else to support them along the way…

Theme 6: Children Present with Unique Perceptions and Needs Related to Grief and Bereavement

Participants discussed the significant considerations of working with children at end-of-life and those with life-limiting medical conditions. A major theme found within the study related to the unique perceptions and needs of children related to grief and bereavement. Participants discussed that working with children always included working with the family unit—a significant difference when working with adults. Additionally, children and youth understand, process, and communicate differently, so the way that children and youth process and experience grief and loss also varied. Ultimately, participants acknowledged an awareness on development, language, and family-systems when working with children and youth and how those considerations were a major focus in this work.

June talked about having to take into account the differences in working with this group, and how she wasn't sure she wanted to work with children for fear of, "the sadness of such little lives;" however, she further remarked, "I found that I really did appreciate their insight more than adults quite a lot of the time." Many participants discussed the increased insight of children and their willingness to engage in conversations related to bereavement more than adults. Parker shared insight into these experiences particularly when working with the school system:

> …goodness, the children just launch themselves into it, they are really ready for it. I think they really need it, they come from schools where the schools are desperately trying to acknowledge the fact that mum's died, or whoever has died. The schools are very quick to refer the children to us, can you please do something with this kid? They're being disruptive in school, we don't know what to do, so there's a great fear around actually just sitting down with Johnny and talking about the fact that his mum's died and what that means to him.

Additionally, building relationships looks different when working with children and youth. Ella further explored a child's ability to connect in this way:

> Especially when it comes to children, my experience is that they can sense anyway what kind of person you are. They can sense whether you know what you're talking about or…you know your own reason for being here, and they know whether you are strong enough to hold that or not…. They will often try and find out anyway at the beginning; some children will test your boundaries…relentlessly…just to see how you're coping with something that they can't hold in and they can't cope with.

Participants also discussed the differences on stigma regarding death for children and adults. Brenda described it as a willingness to engage in conversation around child death due to its shock factor:

> …at this point in time in this society there's less of a stigma about talking about child death than other death, I think probably it's for people so traumatic and so shocking that a child should die now at this point in time in our society from an illness, which is mainly the children in the hospices that… probably more openly talked about than adult death even, but I, yeah, it's still quite a closed issue I think generally speaking…

Mary further expanded on the stigmas present around death, focusing on a willingness for children to engage in conversation around death and dying. Mary shared that, "I still find today that people are not comfortable about talking about it [death], …I think children will ask about it and…people don't know how to react to it, and how to support them…." Participants identified that in the children's hospices, the focus on child bereavement work allows children to be a part of the conversation.

Developmental Considerations. One of the subthemes that emerged when working with children includes the importance of developmental considerations. Participants noted that children process information differently based on their current stage of development. Additionally, that children and youth will continue to be affected by a loss at various stages in life as they age. Ella discussed developmental considerations in the way that children process information and emotions:

> You can't see children where all of a sudden something falls into place you know and they've worked through something and you know they're going to be ok, you know, they've got themselves into this place of, "it's ok," it's still difficult and it will remain difficult to have lost someone... and you know, whether it's a parent or a sibling or whatever, and you know from your own experience that it will come up throughout life….It's not something that is finished, and then they're sent off…

The Power of Words. The second subtheme to emerge relates to the impact of language. Participants discussed the significance of using intentional, developmentally appropriate language with children when doing bereavement work. The power of words signifies that language in bereavement work carries weight and impacts one's understanding and ability to cope. Participants reiterated that using the concrete language such as, "dead," "death," and "died," were appropriate to meet children's needs. Harper recalled an example of appropriate language when working with a client:

> I'm always sure to, especially if I'm working with children to say "death" and "dying." "I'm really sorry your sister died," I don't use terms like "go to sleep" you hear that a lot, that's not what happened, they didn't go to sleep, they died, they're gone. Yeah, I think people find it really hard to talk about death and dying. It's scary, it's a scary subject… I find it more important when I'm working with children to use those words because um, I've heard of children who were scared to go to sleep because they've been told their sister went to sleep when actually, they've died, and it can just become really muddled and it's really important to just be really clear with children and not.

June further talked about empowerment through language, stating that practitioners need to lean into direct language around death:

> I think that does make all the difference to families when they're here with their children that they are in as empowered a position as they can be when they feel like they haven't got any control at all. I think part of that is in the language that we use and not being afraid of words.

Summary

The purpose of chapter four was to present the results of this phenomenological research study. This researcher interviewed a total of 15 participants utilizing a semi-structured interview format to explore the lived experiences and perceived levels of preparedness of child bereavement workers in the United Kingdom. A total of six themes were identified: (a) foundation of hospice is holistic, (b) bereavement work entails a unique developmental process, (c) nature of the work requires additional support and supervision, (d) perceptions of death and disabilities matter, (e) death work allows for a greater focus on life, and (f) children present with unique perceptions and needs related to grief and bereavement. In chapter five, the researcher will report the results in light of the literature, discuss limitations to the study, and identify implications for future practice including suggestions for counselors and counselor educators.

CHAPTER FIVE: DISCUSSION

Chapter one introduced literature related to grief, bereavement, existential theory, and mental health. The researcher then proposed a study to explore the lived experiences of child bereavement professionals. More specially, professionals who worked in children's hospices in the United Kingdom. Chapter two explored literature regarding the history of loss, grief theory, death education, existential theory, children's hospices in the United Kingdom, and its relation to counseling and counselor education. Following, in chapter three, the methodology of this phenomenological-qualitative research design was outlined. Chapter four then presented the results including themes and subthemes that emerged from the data. The current chapter includes: the purpose of the study, an overview of methodology, discussion of results, limitations of the current study, recommendations for future research, implications for counseling and counselor education, and the conclusion.

The Purpose of the Study

Through the study, the researcher sought to gain a deeper understanding of bereavement work through the perceptions and experiences of bereavement professionals in children's hospices. Thus, the purpose of the study was to explore the feelings, experiences, and education of bereavement support professionals working in children's hospices in the United Kingdom. The research question for this study was:

> "What are the experiences and perceived levels of preparedness of bereavement professionals' working with bereaved children, families, and young people?"

The following objectives were also identified for exploration in the study:

1. Bereavement support professionals' perceptions of their work on both a professional and personal level.

2. Specific training and other contributory factors that bereavement support professionals feel most important and useful in their work.
3. Content and practices of how counselor educators and supervisors prepare students to address the effects of grief and loss as they relate to children, young people, and the wider family system.
4. Bereavement professionals training experiences related to issues of diversity and cultural differences.

Findings are presented with respect to the research question and objectives of the study.

Methodology Overview

A phenomenological-qualitative research design was utilized to gain a deeper understanding of bereavement work through the experiences of individuals who work directly with issues of death and dying in children's hospices. Due to the number of children's hospices in the United Kingdom compared to the United States (*About Us,* n.d.-a), the lived experiences of child bereavement professionals in the United Kingdom were explored. Using Moustaka's (1994) modification of the Stevick-Colaizzi-Keen method, this researcher analyzed the qualitative data from 15 participants who completed semi-structured interviews. Guided by the research question and objectives of the study, the researcher also analyzed the data using an existential theoretical framework to help conceptualize the findings. A total of six themes and various subthemes were identified and are listed below:

- *Foundation of Hospice Is Holistic*
    - Bereavement Professionals Provide Holistic Care Through Authentic Presence
    - Hospice Work Requires Honoring Choice and Flexibility for Families
    - Hospice Allows for Greater Flexibility for the Practitioner

- *Bereavement Work Entails a Unique Developmental Process*
    - A Calling to the Work
    - Developing a New Relationship with Death
    - Practitioners Develop a Concern for “Getting It Right’”
- *Nature of the Work Requires Additional Support and Supervision*
    - Bereavement Preparation is Inconsistent
    - Qualification Focus Emphasizes Emotional Intensity of the Work
- *Perceptions of Death and Disabilities Matter*
- *Death Work Allows for a Greater Focus on Life*
- *Children Present with Unique Perceptions and Needs Related to Grief and Bereavement*
    - Developmental Considerations
    - Power of Words

Discussion of Results

Although the literature included a vast amount of information on grief and bereavement, the experiences of professional bereavement counselors remained underexplored (Dunphy & Schniering, 2009; Kouriatis & Brown, 2011). The results of this study aimed to address a gap in the literature regarding bereavement support professionals work with death, grief, and bereavement. The results will be explored in reference to the research question and objectives of the study. The themes and subthemes worked together to answer the research question.

What are the Experiences and Perceived Levels of Preparedness of Bereavement Professionals' Working with Bereaved Children, Families, and Young People?

The experiences of bereavement professionals were explored through the qualitative interview process. The researcher asked participants to describe their experiences as a bereavement support professional, their journey to this career, and the way in which their experiences aligned (or did not align) with their expectations coming into their role. Participants were additionally asked questions related to the most rewarding/challenging aspects of their work, where they garnered support, self-care practices, if they felt specific qualities were needed to work as a bereavement support professional, including experiences of preparation and education. Themes across participants indicated commonalities in their view of hospice work, their perceptions of death and disabilities, the developmental process of working in bereavement, the unique needs of working with children and youth, and recognizing a greater focus on life.

Participants all identified finding meaning in their work as a bereavement support professional. Due to the emotional significance of end-of-life work, this researcher was not surprised with the findings; however, the uniqueness from which professionals *identified meaning in their work,* to how that paralleled with the meaning professionals *focused on with their clients,* was a unique finding. This was significant in the way participants simultaneously derived meaning in their own work, by helping others do the same. Participants reported the importance of helping families create meaning through choice and empowerment during their child's illness and at end-of-life. This was congruent with the theoretical framework as the literature noted that existentialism included a focus on the givens of the human condition in a way that examined the choice and responsibility individuals have in their lives, allowing them to confront the anxieties that exist within existence (Alegria et al., 2016; Fernando, 2007). These findings also supported the understanding that an existential foundation includes a "search for meaning" and "self-actualization" (McClatchey & King, 2015).

The way participants focused on helping clients find meaning was a therapeutic focus with their clients. Participants looked at the importance of allowing choice and freedom in death work by allowing families to be a part of the process. It was shared that clients were able to discover, or rediscover, their purpose and meaning for existence—aligning with the literature on existential theory (Lemay & Wilson, 2008). Through a focus on meaning and purpose, the therapeutic process allowed clients to take an in-depth look at the ways in which they view their world (Alegria et al., 2016) in order to allow for authentic choice with end-of-life decisions. What was interesting to the researcher was the focus and awareness on cultural needs and the impact of the bereavement suites for families. Through this focus, bereavement professionals worked to honor the way clients and their families lived, to continue to honor them through end-of-life.

Participants were also noted throughout the data to describe their vocation as a "privilege" and often expressed feeling "called to the work." Some participants shared that their personal experiences with death had impacted their work in bereavement, often describing being called to the work as a way to address the support they did or did not receive in their own personal grief experience. Participants who shared their own loss experiences, particularly related to child loss, discussed the importance of doing their own work and obtaining consistent supervision. The researcher recognized this as a significant finding due to the theme that spoke to *nature of the work requires additional support and supervision*. The researcher recognized many participants felt connected to the work either through personal experience or an investment in the advocacy of grief and bereavement support; an important distinction that participants identified related to consistent supervision and on-the-job support. This was significant to participants in order to maintain self-awareness and an understanding of a practitioner's grief vs. the client's grief. The literature further supported this by recognizing that doing one's own death work speaks to a focus on ethical practice and helps to address any potential blind spots when engaging with clients (Dunphy & Schniering, 2009; Worden, 2009). The literature further suggested that, “If it has been adequately integrated, the counselor’s experience with a similar loss can be beneficial and useful in work with the client” (Worden, 2009, p. 252).

The counselor has been identified in the literature as crucial to the therapeutic process (Chan & Tin, 2012; Crunk & Barden, 2017); therefore, one’s personal attitudes on death and bereavement may not only affect the counseling work, but ultimately the therapeutic relationship (Chan & Tin, 2012). This researcher recognized the importance of this in terms of implications for counselors and counselor educators due to the universal nature of grief and loss. The literature reiterated that mental health professionals will ultimately bear witness to clients struggling with issues related to grief and loss regardless of the presenting concern (Cacciatore et al., 2015; Dunphy & Schniering, 2009; Harrawood et al., 2011; McClatchey & King, 2015; Morgan, 2009). Furthermore, the literature stated that counselors who had an understanding of their own death attitudes and self-awareness reported more comfort discussing and expressing personal feelings of loss with clients (Ober et al., 2012), also present throughout the findings. As such, counselor educators may need to explore consistent grief and loss education and the effect that grief work may have on a practitioner’s ability to deal with personal death awareness and feelings of death anxiety.

Participants also reported that bereavement work did not require the personal experience of having been bereaved of a child, but a willingness to bear witness to one’s suffering, including the courage to lean into the experience of loss. Counselors working with children at end-of-life, those living with life-limiting conditions, and bereaved families, have to bear witness to some of the most devastating moments in a person’s life— including extreme feelings of pain, suffering and sorrow. Therefore, as noted in the literature, understanding the impact of death and bereavement, especially as it relates to children, should be of importance for mental health professionals (Ayyash-Abdo, 2001; Ener & Ray, 2018); not only for professional practice, but to cope with one’s own loss experiences as well (Chan & Tin, 2012).

Even though the literature suggests that the impact of bereavement work on clinicians is lacking, participants’ reported understanding of the impact of bereavement work remained consistent with literature on Worden’s ways that working with the bereaved can impact mental health professionals. Worden (2009) discussed three ways individuals were impacted by bereavement work: (1) counseling the bereaved makes one aware of their own losses; (2) through an exploration of one’s personal losses, the counselor able to identify resources that were, or were not helpful, to the counselor’s own grief process; and (3) being exposed to one’s own grief brings insight into the clinician’s limitations for working with grief and bereavement, allowing them to make ethically informed decisions.

This researcher recognized the unique aspect of consistent supervision discussed by the participants as a significant finding from the data. Supervision was provided by the children’s hospice and occurred regardless of one’s clinical status (i.e., needing supervision to practice independently). Participants described that engaging in consistent supervision allowed for more focus on overall well-being, case conceptualization, and an awareness of the work on one’s emotional state. Consistent with Hayes et al. (2007), therapists’ overall well-being has an impact on quality of therapy; therefore, this researcher wondered if consistent self-reflection through supervision was correlated to other themes present in the study including clinicians’ overarching focus on life vs. death, reported consistent self-care practices, and longevity in an emotionally intense field. This researcher continued to identify consistent supervision as an important finding and one that could lead to future research and a focus for the counseling field to reduce burnout.

Participants further discussed the qualities they felt important to bereavement support work. Most participants spoke to resiliency, strength, integrity, and the ability to hold one's emotions as being paramount to the work with death and dying. Furthermore, clinicians highlighted a need for more training and awareness to aid in developing these qualities and to address the emotional intensity of the work. Participants identified that overall bereavement training was lacking, and often unavailable to individuals or practitioners. Additionally, when bereavement training was available, it was presented in lectures or trainings often on-the-job, or through the hospice itself. In fact, no participants reported having a stand-alone course on grief and bereavement during their education—regardless of background. Furthermore, only some participants stated that they had courses in their educational experience that mentioned grief; yet, when it was brought up in coursework, participants often reported that it was brief, or part of a larger topic area. This researcher found those results to be consistent with the literature on grief and loss education. Information presented on current training opportunities in death work reported that most individuals participated in seminars and/or continuing education workshops rather than formal graduate programming (Hannon & Hunt, 2015; Wass, 2004).

Throughout the data, only a few participants mentioned information related to grief theories when asked about areas of preparation. In particular, one participant spoke to their use of Kubler Ross' stages of grief as the main theory utilized in practice. The researcher recognized this as an important part of the data due to information presented in the literature related to a push for education on more modern grief theories. The literature highlighted the importance of individualized grief support, as no one theory can be applied collectively to grief issues (Cicchetti et al., 2016; Doughty et al., 2011). Additionally, Ober et al. (2012) reflected that in a study on counselors' training, experience, and competencies in grief counseling, participants were asked to identify familiarity with grief theories, with most participants reporting knowledge of Kubler-Ross' five stages of grief, but little knowledge regarding other theories, including those related to meaning reconstruction or attachment. This further highlighted a need for more consistent standards around death education, and/or training to include not only a history of grief theory, but an understanding of more modern theory as well. More importantly, as noted by participants, standards need to include education with a particular focus on self-awareness, emotional integrity, death anxiety, and personal death awareness.

This researcher also identified the significance of inconsistent education and training noted by participants. Wass (2004) noted that the inclusion of death education in short formats, such as with lectures or seminars, did not allow for exploration regarding professional or personal feelings of death, death anxiety, or comfort working in the area of bereavement. Participants in the study further emphasized this point by stating that individuals who worked in bereavement need to have a deeper understanding of their own experiences with grief and loss and they ways in which it may impact their work. Bereavement support professionals often discussed that the lack of bereavement training was seen through a lack of personal death awareness and discomfort in having conversations around death, particularly when it came to appropriate language (i.e., saying the word death or dying). Participants stated that this was especially important when it came to working with children and youth.

Another significant finding related to the differences in working with adults compared to children and youth. Although the death of a loved one could be considered traumatic for any individual, the literature reiterated that the death of a child was considered one of the most traumatic (Morgan, 2009). The researcher identified various considerations in working with children in the area of grief and bereavement. Participants noted that children and youth had a deeper engagement with concepts related to grief and loss and a greater willingness to engage in conversations surrounding these topics than adults. Although this was not identified as clearly throughout the literature, this researcher considered this to be an important finding due to its implications for trainings, clinical intervention, and the opportunities to discuss death. Additionally, the researcher wondered if the ability of children to speak more freely was due to less societal pressure (also noted within the findings) ultimately contributing to this theme from participants.

Similarly, the significance of language and developmental considerations were found to be consistent across participants. Bereavement support professionals identified that children and youth have unique developmental needs compared to adults related to cognition and emotional awareness. Most noticeably, participants spoke to the fact that children will continue to grieve in new ways throughout their lives as they bring in new aspects of their development at each stage. This researcher recognized the importance of this as an area of clinical practice and education for counselor educators. The ability to work with children and youth presents unique considerations that require training and education. However, the literature found that when death education was available, there was a greater focus on individuals at later stages of life (adults) than with children (Bagatell et al., 2002). The researcher ultimately identified throughout the interviews that an awareness of the unique perceptions and needs of children was important not only in bereavement work, but all aspects of mental health.

Participants also described their experience witnessing holistic care as a driving force in hospice work. Participants spoke to a model of care that utilized an all-inclusive lens to meet community, physical, social/emotional, cultural, and spiritual care needs. According to Dangel (2002), pediatric palliative care programming supports children, youth and their families who are living with life-limiting conditions in a holistic way to include respite services and death and bereavement support. Congruent with the literature, participants noted that through their hospice work, families were at the heart of care. Through a holistic model, the cultural, spiritual, emotional, social, and physical needs were all recognized as equally important. Participants spoke to the impact of this on families and the ability to meet families where they were.

There were two specific ways that participants frequently spoke to as to how they experienced holistic care in their bereavement work—through cultural and spiritual considerations as a part of end-of-life care. Participants discussed the importance of encouraging discussions and responding to families' cultural and religious preferences for end-of-life care related to their child. This aligned with the literature on adaptive grieving styles, a model for counselors to explore the unique experience of grievers utilizing a holistic view—including personality, experience, and culture (Doughty & Hoskins, 2011). The focus of this model allows for an understanding of the family's culture in order to fully recognize and appreciate the individualized nature of one's grief experience. According to the literature, this is a place that also allows for more targeted education in counselor education as well, "It is important for counselors and counselors-in-training to recognize clients' natural adaptive styles and how they may or may not fit into cultural expectations" (Doughty & Hoskins, 2011, p. 32-33). This researcher considered this an important finding for implications on counselor education.

Choice and flexibility were additional areas of focus among participants. A subtheme that emerged focused on the significance of choice as a means to cope with the reality of death. Participants discussed allowing families the chance to choose when, and how, to say goodbye to their loved one including the cultural and spiritual needs noted above. One way to offer space and time to grieve was through bereavement suites. Participants often reported that this was a way to give time back to the family as well as help them cope with and understand the loss. One participant discussed how utilizing the suite gave families an opportunity to simply focus on saying goodbye, instead of having to directly leave the hospital without the child following the death. The combination of this supports the literature regarding an existential focus on life—one cannot simply be a passive observer of their experience; instead, they must take ownership and actively engage in their being-in-the-world to allow for freedom and choice ultimately allowing for greater meaning (Colosimo et al., 2018; Manis & Bodenhorn, 2006; Sørensen et al., 2018; Yalom, 2008). Ultimately, this researcher recognized the importance of training, education, and consistent support for bereavement support professionals. This was also identified throughout the literature as a need for mental health professionals to be prepared to work with all aspects of grief and loss (Doughty et al., 2011). The prevalence of loss and implications of grief on mental health supports the need for mental health educators, students, and providers to explore the significance of death.

Limitations of the Current Study

The main limitations to the study focus on the recruitment of participants. All participants were recruited from children's hospices in the United Kingdom. Due to a utilization of a snowball sampling technique, there may also be limitations to the specific connections used for recruitment; not allowing for a more random sampling procedure. Another limitation included the data collection timeframe. Due to the researchers traveling to the United Kingdom, a shorter timeframe was used to conduct interviews. Additionally, due to three different members of the research team conducting semi-structured interviews, a potential limitation could include leading questions based on emerging thoughts from the researcher(s) during data collection. Despite these limitations, the researcher believes the post-study benefits outweigh the limitations.

Recommendations for Future Research

The purpose of this study was to explore the lived experiences and perceived levels of preparedness of bereavement support professionals working in the areas of death and dying. Throughout the literature and findings, there were opportunities to continue or further research. One area of potential research may include exploring clients' experiences of counselors at end-of-life. This would involve counselors work with the dying and/or families of the bereaved. This researcher believes that research in this area may prove impactful not only for children, but practitioners' work with adults as well. Another area of focus could include comfort with death in counseling work. Currently, the research focuses on beginning counselors experience with comfort around death; therefore, additional research may prove impactful with counselors who have been in the field for longer than five years.

This researcher also noted that there exists a lack of information regarding overall therapist well-being, burnout, and compassion fatigue when working in the area of bereavement; particularly when working with children and youth. Additionally, more research may further explore findings from the study that relate to the significance of continued support and supervision past requirements of clinical licensure, and its impact on clinician satisfaction and burnout. This researcher additionally identified that research on the application of grief and loss training may be important to the integration of grief education as a consistent area of focus in training programs. Finally, a study on the difference between children's hospices, or hospices in general, between the United States and the United Kingdom may prove impactful for areas of research, clinical intervention, and education for mental health practitioners.

Implications for Counseling and Counselor Education

Lastly, in the process of conducting this study and reviewing the literature, a number of implications for counseling and counselor education arose. One main area of consideration is in the need for consistent grief and bereavement training in counselor education. The participants discussed a lack of consistent death education or reported coursework that mentioned grief briefly as a part of a larger course. Counselor education may consider looking at incorporating a stand-alone grief course that highlights grief theory, but also focuses on the emotional intensity of the work as indicated in the findings of this study. Participants noted that although grief models were important, the ability of counselors to sit with and hold their own emotions was paramount with clients. Additionally, coursework or training needs to allow for a greater focus on individual awareness of death, death anxiety, and one's own grief responses. A greater understanding of emotional awareness may assist counselors in not only understanding their own grief response but increase comfort on the topic and allow practitioners to recognize the difference between maladaptive coping compared to a normative grief response.

Another area of consideration for counseling and counselor education is that of training related specifically to working with children and youth. A focus on developmental considerations when working with children related to grief, bereavement, and death would allow for continued insight into this specialized population. Furthermore, according to the findings from this study, a focus on appropriate, honest, and concrete language on death and dying is needed. Counselor education could include this in coursework as a way to help students discuss issues related to grief and loss with clients including children, youth, adults and families. This is also an important area of focus for not only mental health counseling, but school counseling as well. As noted in the study, death and grief have significant impacts on school systems. Schools often report being uncertain on how to respond to death-related losses and often look to community practitioners for help.

Another implication for counseling and counselor education is the focus on consistent supervision and self-care practices represented by the bereavement support professionals in this study. All of the participants discussed the important of clinical supervision at the job site, past the requirement of clinical licensure. This may be an area to explore for counselor education in looking at the bereavement model of support as a way to offer supervision. Additionally, the focus on consistent self-care practices as an expectation, may prove impactful for counselors-in-training and those supervising new counselors as a way to alleviate burnout and address compassion fatigue.

Ultimately, the biggest implications for counseling and counselor education involve the awareness of death education as an area of study. As identified in the study, there are characteristics that bereavement support professionals possess such as resiliency, courage to have uncomfortable conversations, and identifying appropriate boundaries. These are all areas that are important to current counseling practice but can be emphasized to prepare for work with the dying and the bereaved. A focus on cultural implications and an awareness of holistic care practices may also prove beneficial for counselors and counselor educators. Lastly, these areas of focus may prove advantageous in working toward integrating death education as a focus in both the ACA code of ethics and CACREP standards for clinical standards of practice.

Conclusion

Chapter five explored the findings of this study in light of the research question and connection to the literature. The purpose of the study was to explore the lived experiences and perceived levels of education of bereavement support professionals working at children's hospices in the United Kingdom. A total of six themes and various subthemes were identified related to holistic care, personal/professional development, meaning in the work, perceptions of death and disabilities, supervision and support, and the bereavement considerations working with children and youth. Participants spoke to finding meaning and connection in the work, as well as implications for education and preparation in this area. The researcher further explored the findings and implications for counseling and counselor education including a focus on death competence, supervision, and grief education. Limitations of the study and recommendations for future research were also discussed.

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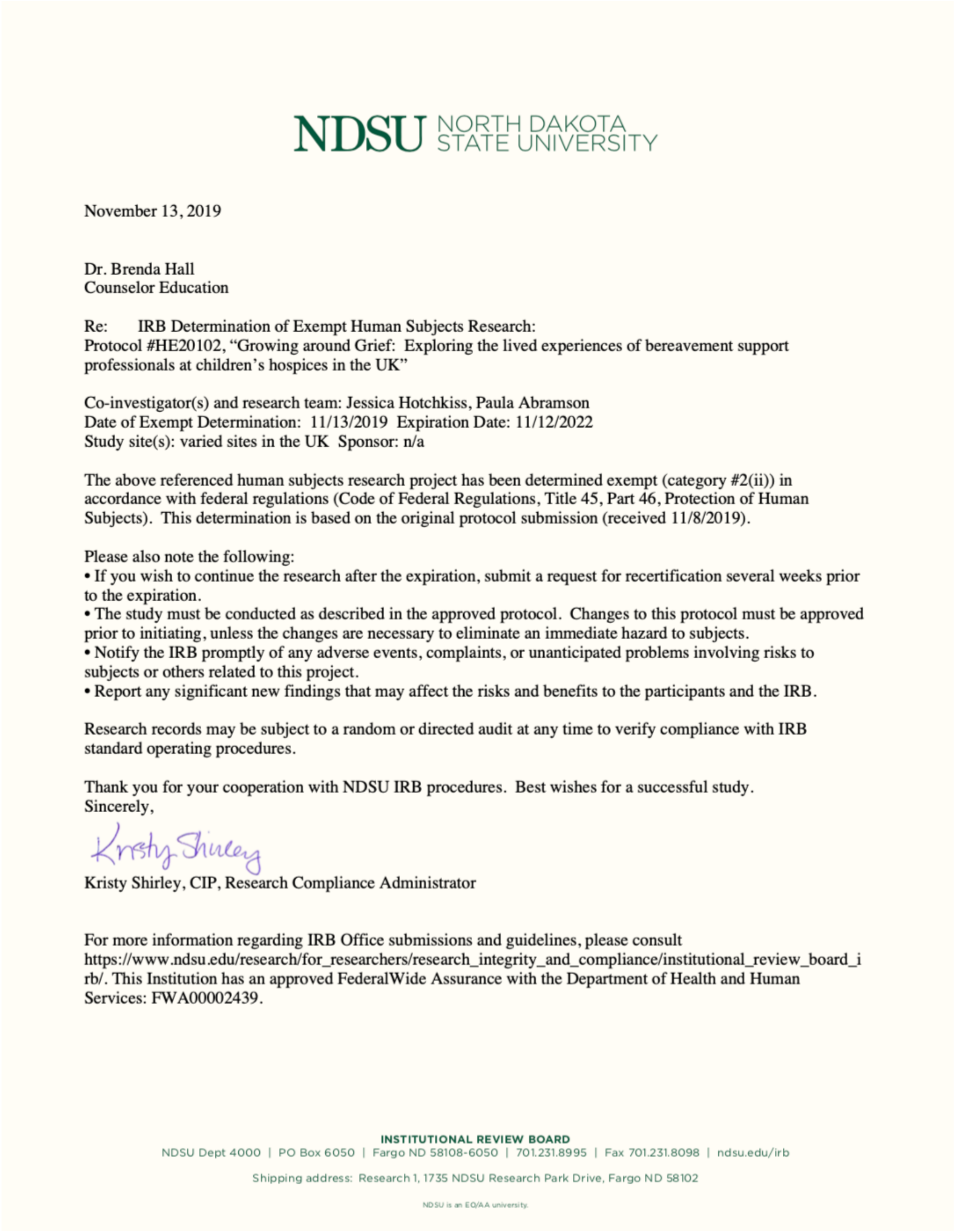
APPENDIX A. INTERVIEW QUESTIONS

1. How would you describe your experiences as a bereavement support professional?
    a. In what ways have these experiences aligned (or not aligned) with your expectations when you began this work?
2. Could you talk about how you came to work in this specialist area?
    a. What helped you prepare the most?
    b. What aspects of education or training influenced you?
    c. Looking back, is there anything you would have liked to know before you began this work?
3. What specific qualities do you think are needed to work in this specialist area of bereavement support?
4. What do you find the most rewarding about your work?
5. What do you find the most challenging about your work?
    a. Where do you get your support from?
    b. How do you take care of yourself?

APPENDIX B. IRB APPROVAL LETTER



NDSU NORTH DAKOTA STATE UNIVERSITY

November 13, 2019

Dr. Brenda Hall
Counselor Education

Re: IRB Determination of Exempt Human Subjects Research:
Protocol #HE20102, "Growing around Grief: Exploring the lived experiences of bereavement support professionals at children's hospices in the UK"

Co-investigator(s) and research team: Jessica Hotchkiss, Paula Abramson
Date of Exempt Determination: 11/13/2019 Expiration Date: 11/12/2022
Study site(s): varied sites in the UK Sponsor: n/a

The above referenced human subjects research project has been determined exempt (category #2(ii)) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects). This determination is based on the original protocol submission (received 11/8/2019).

Please also note the following:

- If you wish to continue the research after the expiration, submit a request for recertification several weeks prior to the expiration.
- The study must be conducted as described in the approved protocol. Changes to this protocol must be approved prior to initiating, unless the changes are necessary to eliminate an immediate hazard to subjects.
- Notify the IRB promptly of any adverse events, complaints, or unanticipated problems involving risks to subjects or others related to this project.
- Report any significant new findings that may affect the risks and benefits to the participants and the IRB.

Research records may be subject to a random or directed audit at any time to verify compliance with IRB standard operating procedures.

Thank you for your cooperation with NDSU IRB procedures. Best wishes for a successful study.
Sincerely,

Kristy Shirley

Kristy Shirley, CIP, Research Compliance Administrator

For more information regarding IRB Office submissions and guidelines, please consult https://www.ndsu.edu/research/for_researchers/research_integrity_and_compliance/institutional_review_board_irb/. This Institution has an approved FederalWide Assurance with the Department of Health and Human Services: FWA00002439.

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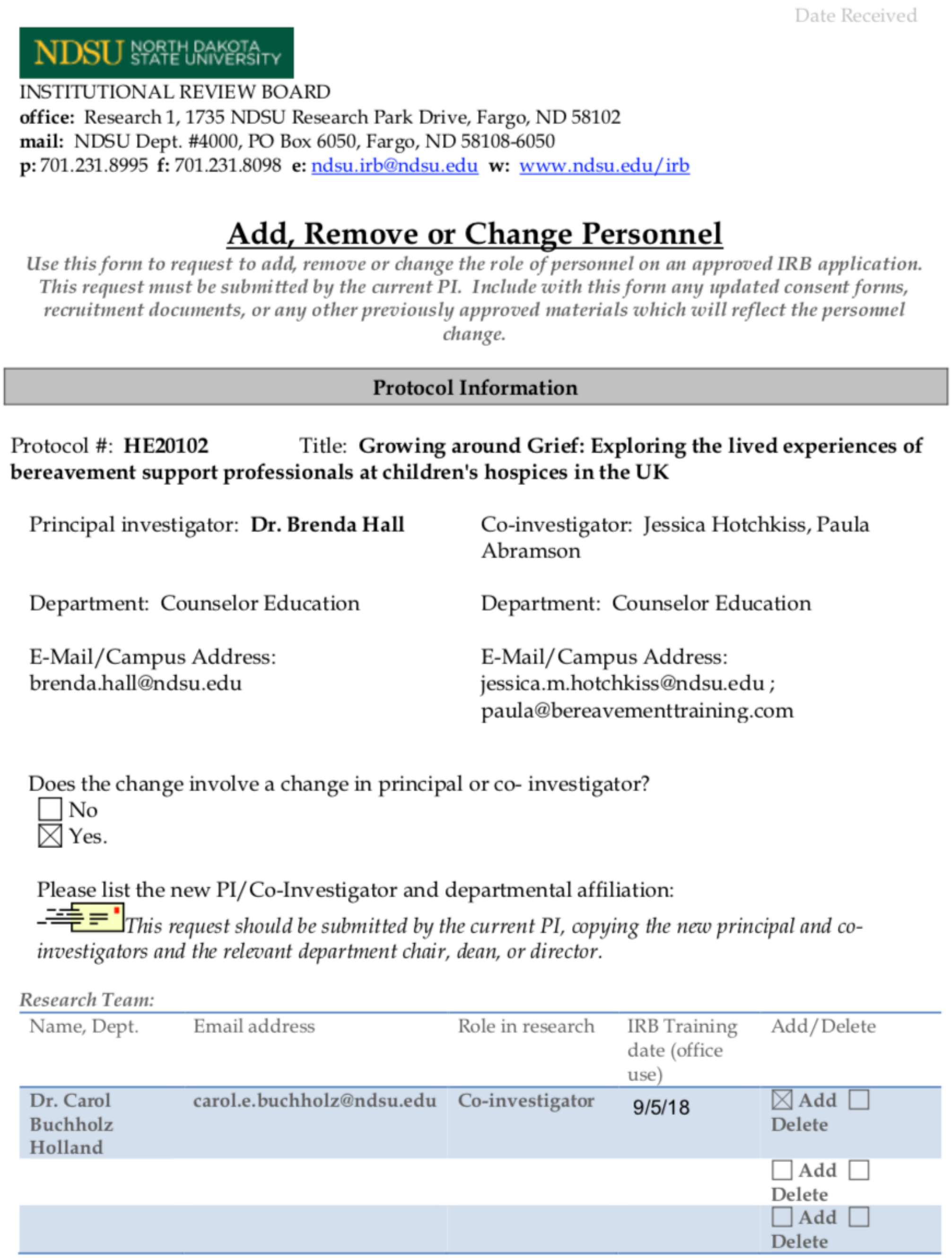
NDSU Dept 4000 | PO Box 6050 | Fargo ND 58108-6050 | 701.231.8995 | Fax 701.231.8098 | ndsu.edu/irb

Shipping address: Research 1, 1735 NDSU Research Park Drive, Fargo ND 58102

NDSU is an EO/AA university.

APPENDIX C. IRB APPROVAL ADD PERSONNEL FORM



Date Received

NDSU NORTH DAKOTA STATE UNIVERSITY

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Add, Remove or Change Personnel

Use this form to request to add, remove or change the role of personnel on an approved IRB application. This request must be submitted by the current PI. Include with this form any updated consent forms, recruitment documents, or any other previously approved materials which will reflect the personnel change.

Protocol Information

Protocol #: **HE20102** Title: **Growing around Grief: Exploring the lived experiences of bereavement support professionals at children's hospices in the UK**

Principal investigator: **Dr. Brenda Hall**	Co-investigator: Jessica Hotchkiss, Paula Abramson
Department: Counselor Education	Department: Counselor Education
E-Mail/Campus Address: brenda.hall@ndsu.edu	E-Mail/Campus Address: jessica.m.hotchkiss@ndsu.edu ; paula@bereavementtraining.com

Does the change involve a change in principal or co- investigator?
☐ No
☒ Yes.

Please list the new PI/Co-Investigator and departmental affiliation:

This request should be submitted by the current PI, copying the new principal and co-investigators and the relevant department chair, dean, or director.

Research Team:

Name, Dept.	Email address	Role in research	IRB Training date (office use)	Add/Delete
Dr. Carol Buchholz Holland	**carol.e.buchholz@ndsu.edu**	**Co-investigator**	9/5/18	☒ **Add** ☐ **Delete**
				☐ **Add** ☐ **Delete**
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Conflict of Interest disclosure.
Does any investigator responsible for the design, conduct or reporting of the project (including their immediate family members) have a financial, personal or political interest that may conflict with their responsibility for protecting human participants in NDSU research?
(*SOP 6.2 Conflict of Interest in Human Research, Investigator and Research Team)*

☒ No – As PI, I attest that I have conferred with my co-investigators and key personnel and confirmed that no financial, personal or political interests currently exist related to this research.
☐ Yes – Describe the related financial, personal or political interests, and **attach documentation of COI disclosure and review** *(as applicable)*.

Financial, personal or political interests related to the research (the sponsor, product or service being tested, or a competing product or service) may include:

- compensation (e.g., salary, payment for services, consulting fees)

- intellectual property rights or equity interests
- board memberships or executive positions
- enrollment or recruitment bonus payments

(Refer to *NDSU Policy 151.1, External Activities and Conflicts of Interest, and NDSU Policy 823, Financial Disclosure – Sponsored Projects* for specific disclosure requirements.)

Brenda Hall via email 8/10/2020

Principal Investigator signature, date

In lieu of a written signature, submission of this report via the Principal Investigator's NDSU email constitutes an acceptable electronic signature.

- - - - - - - - - -FOR IRB USE ONLY - - - - - - - -

☒ Approved

IRB Signature: Kristy Shirley Date: 8/10/2020

APPENDIX D. INFORMED CONSENT DOCUMENT

NDSU North Dakota State University
Counselor Education and Supervision
SGC Building, 1919 N. University Drive
Fargo, ND 58108-6050
(701) 231-7202

Title of Research Study: "Growing around Grief: Exploring the lived experiences of bereavement support professionals at children's hospices in the UK."

This study is being conducted by: Jessica Hotchkiss is a Ph.D. student in Counselor Education and Supervision at North Dakota State University. Dr. Brenda Hall (Department of Counselor Education and Supervision at North Dakota State University) is Jessica's instructor and is the primary investigator on record. Dr. Hall's phone number is +1 701-231-8077. Paula Abramson is a psychotherapist, formerly of Child Bereavement UK and the founder of Bereavement Training International based in the UK. She is the third member of the research team. Paula's number is + 44 0771-263-1509.

Why am I being asked to take part in this research study? The researchers are interested in learning about your perceptions and experiences as a bereavement support professional working in a children's hospice. We are seeking fifteen to twenty individuals to be participants in this study.

What is the reason for doing the study? Unfortunately, topics of bereavement in the United States are underrepresented in counselor education training and supervision (Breen, 2010; Cacciatore, Thieleman, Killian, & Tavasolli, 2014) especially in relation to death and dying. Through this study, the researchers seek to gain a better understanding about bereavement work through the perceptions and experiences of individuals who work directly with issues of death and dying in children's hospices. Specific objectives include understanding more fully:

1. Bereavement support professionals' perceptions of their work on both a professional and personal level.
2. Specific training and other contributory factors that bereavement support professionals feel is important and useful in their work.
3. Content and practices of how counselor educators and supervisors prepare students to address the effects of grief and loss as they relate to children, young people, and the wider family system.
4. Bereavement professionals training experiences related to issues of diversity and cultural differences.

Using information from this study, the researchers plan to develop bereavement-counseling curriculum for counselor education, and further promote the integration of bereavement work into mainstream counseling practice.

What will I be asked to do? ***OR What Information will be collected about me?***
You will be asked to participate in an interview with one of the researchers for 45-60 minutes. It will be a semi-structured interview with some specific questions (see list of questions attached).

Where is the study going to take place, and how long will it take?
The researchers will come to a place that is convenient for you to conduct the interview. They will make sure that there is a private space so that you may feel comfortable to share information. The interviews will be recorded. Names will not be utilized so that there is minimal risk in terms of identifiers.

What are the risks and discomforts? Possible risks of participating in this study include the loss of confidentiality and emotional discomfort due to subject matter. It is not possible to identify all potential risks in research procedures, but the researchers have taken reasonable safeguards to minimize any known risks to the participant.

Due to the researcher being a mandated reporter (counselor), confidentiality may be broken for the following reasons:
1. If the participant indicates that they will harm themselves or another person.
2. if the participant indicates that they are being physically harmed or financially exploited by another individual.
3. If the participant discloses instances of abuse of children.

What are the benefits to me? A possible benefit from the study is to share your experience and add to our knowledge base related to the work of bereavement professionals. However, you may not get any benefit from being in this research study.

What are the benefits to other people?
Your participation in this study will allow us to obtain information that will be used to improve the quality of bereavement counseling within the counseling profession, especially in the United States.

Do I have to take part in the study? Your participation in this research is your choice. If you decide to participate in the study, you may change your mind and stop participating at any time without penalty or loss of benefits to which you are already entitled.

What are the alternatives to being in this research study? Instead of being in this research study, you can choose not to participate.

Who will see the information that I give?
We will keep private all research records that identify you. Your information will be combined with information from other people taking part in the study. When we write about the study, we will write about the combined information that we have gathered. We may publish the results of the study; however, we will keep your name and other identifying information private. Any identifying information (i.e. name) will be replaced with a number in order to ensure confidentiality. This will take place when the audio-taped interview is typed into text. As a result, no identifying information will be included in the typed interview. The audio-taped

interview will be kept under lock and key when not in use by the researchers. The audiotaped interview will be deleted when the interview has been typed into text format. All materials relating to the study will be kept under lock and key at the researcher's residence when not in use.

If you withdraw before the research is over, your information will be removed at your request and we will not collect additional information about you.

What if I have questions?

Before you decide whether to accept this invitation to take part in the research study, please ask any questions that might come to mind now. Later, if you have any questions about the study, you can contact the researchers: Paula Abramson at paula@bereavementtraining.com or +44 0771-263-1509, Jessica Hotchkiss at Jessica.M.Hotchkiss@ndsu.edu and Dr. Brenda Hall at Brenda.Hall@ndsu.edu or +1 (701) 231-8077 USA.

What are my rights as a research participant?

You have rights as a participant in research. If you have questions about your rights, or complaints about this research you may talk to the researcher or contact the NDSU Human Research Protection Program by:

- Telephone: +1 701.231.8995 or toll-free 1.855.800.6717
- Email: ndsu.irb@ndsu.edu
- Mail: NDSU HRPP Office, NDSU Dept. 4000, PO Box 6050, Fargo, ND, USA 58108-6050.

The role of the Human Research Protection Program is to see that your rights are protected in this research; more information about your rights can be found at www.ndsu.edu/irb .

Documentation of Informed Consent:

You are freely making a decision whether to be in this research study. Signing this form means that

1. you have read and understood this consent form
2. you have had your questions answered, and
3. you have decided to be in the study.

You will be given a copy of this consent form to keep.

____ ____________________
Your signature Date

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Your printed name

____ ____________________
Signature of researcher explaining study Date

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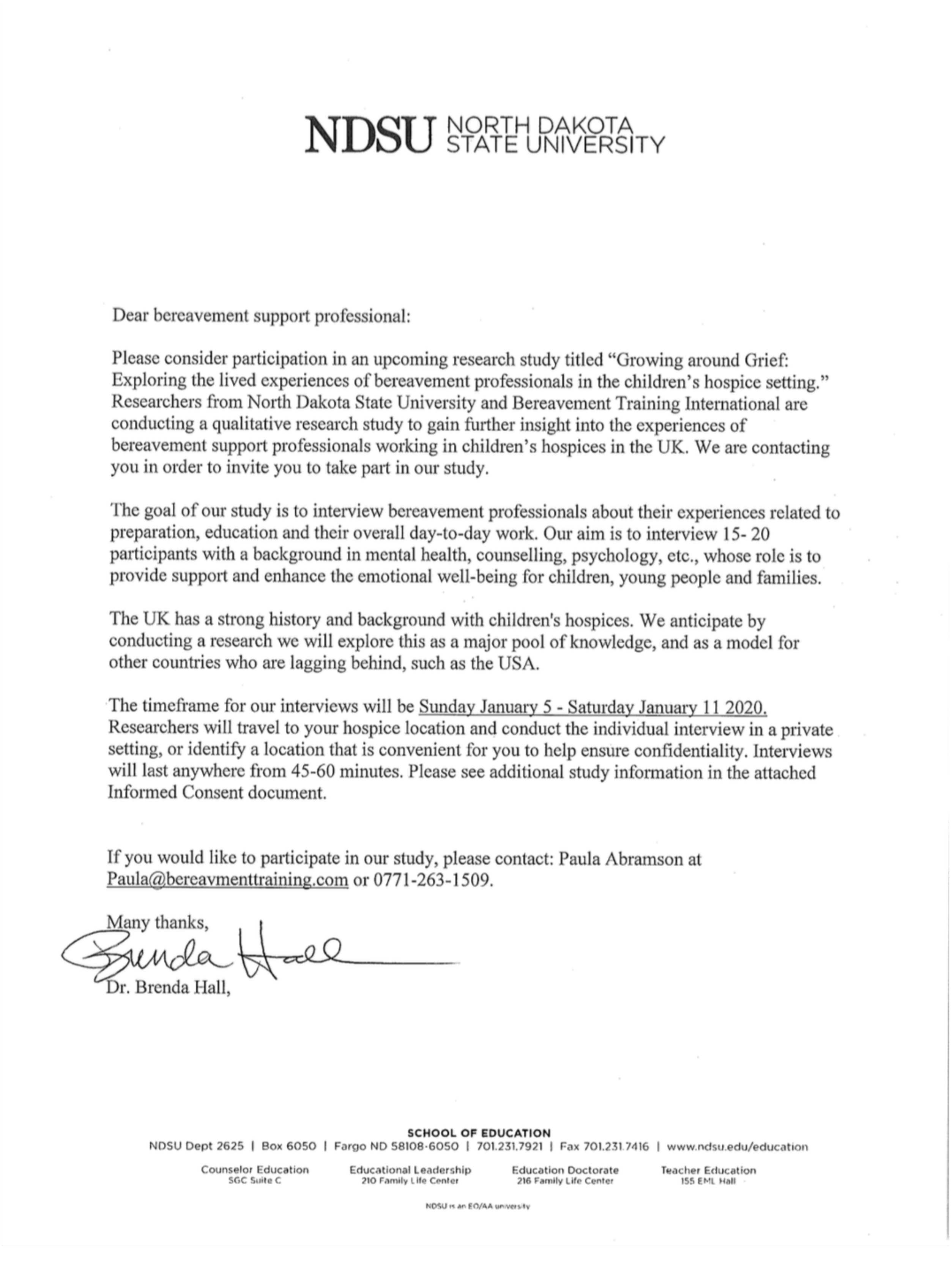
Printed name of researcher explaining study

APPENDIX E. RECRUITMENT EMAIL



NDSU NORTH DAKOTA STATE UNIVERSITY

Dear bereavement support professional:

Please consider participation in an upcoming research study titled "Growing around Grief: Exploring the lived experiences of bereavement professionals in the children's hospice setting." Researchers from North Dakota State University and Bereavement Training International are conducting a qualitative research study to gain further insight into the experiences of bereavement support professionals working in children's hospices in the UK. We are contacting you in order to invite you to take part in our study.

The goal of our study is to interview bereavement professionals about their experiences related to preparation, education and their overall day-to-day work. Our aim is to interview 15- 20 participants with a background in mental health, counselling, psychology, etc., whose role is to provide support and enhance the emotional well-being for children, young people and families.

The UK has a strong history and background with children's hospices. We anticipate by conducting a research we will explore this as a major pool of knowledge, and as a model for other countries who are lagging behind, such as the USA.

The timeframe for our interviews will be Sunday January 5 - Saturday January 11 2020. Researchers will travel to your hospice location and conduct the individual interview in a private setting, or identify a location that is convenient for you to help ensure confidentiality. Interviews will last anywhere from 45-60 minutes. Please see additional study information in the attached Informed Consent document.

If you would like to participate in our study, please contact: Paula Abramson at Paula@bereavmenttraining.com or 0771-263-1509.

Many thanks,

Brenda Hall

Dr. Brenda Hall,

SCHOOL OF EDUCATION
NDSU Dept 2625 | Box 6050 | Fargo ND 58108-6050 | 701.231.7921 | Fax 701.231.7416 | www.ndsu.edu/education

Counselor Education
SGC Suite C

Educational Leadership
210 Family Life Center

Education Doctorate
216 Family Life Center

Teacher Education
155 EML Hall

NDSU is an EO/AA university