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Perspectives of Close Relatives in Pediatric Palliative Care: A Grounded Theory Approach

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This is to certify that the doctoral dissertation by

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has been found to be complete and satisfactory in all respects,
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Walden University
2011

Abstract

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M.S., Emporia State University, 1993

B.A., Washburn University, 1990

Dissertation Submitted in Partial Fulfillment

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Abstract

Pediatric palliative care has recently become a priority in the healthcare field and is implemented at the time of diagnosis rather than days or weeks before the child's death. Social constructivism theory in which humans generate meaning from their experiences was utilized as a general framework to determine the impact of pediatric palliative care on close relatives. The purpose of this grounded theory study was to generate a substantive theory that explains how close relatives such as grandparents, aunts, and uncles of a child with cancer experience palliative care. The participants of the study included close relatives of children in palliative care. Semi-structured interviews and journaling were used to collect data. Initial, focused, and selective coding procedures were used to manage the data and a content analysis of the textual data was performed. Findings from the data suggested a process of *surrendering to the journey* in which close relatives learn to let go of what they cannot control while holding on to what they can control. Social change implications of this study may include improving healthcare programming for close relatives utilizing supportive-expressive measures. This programming may promote mental health of the close relatives who will learn to deal with their adjustment difficulties and improve their coping skills.

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Dedication

This dissertation is dedicated to my son Daegen James Feyh who fought cancer for 2 years passed away at the age of 4. Daegen's spirit touched everyone who knew him. My pursuit of a doctorate degree in psychology was a result of my experience and all that I learned from him. I am dedicating this dissertation to Daegen and to all children and families who continue to fight this dreadful disease. I am confident that one day there will be a cure, but until then I am dedicating my life to understanding the psychological and psychosocial impact of this disease on children and families.

Acknowledgements

First and foremost I would like to acknowledge my Savior Jesus Christ who without his grace would not be able to pursue this degree. Second, I must acknowledge my husband and daughter who have sacrificed so that I may complete my degree and pursue my dreams. They have been supportive, reassuring, and have provided laughter when I was consumed with feeling overwhelmed. I would also like to acknowledge my other family members and friends who have suffered along with me in the pursuit of this degree and have been continuous motivators.

This dissertation would not have been possible without my chair Dr. Ellen Levine who was a constant ray of hope, provider of good advice, and great motivator. Her wisdom and willingness to challenge me in my endeavors led to a great dissertation. Dr. Levine's ever consistent response and shoulder to lean on during the difficult revisions were welcomed. Additionally, I need to acknowledge Dr. Karine Clay my committee member and methods expert who helped me to formulate my qualitative research questions and methods in a way that would be well received. Dr. Clay's continuous motivation and willingness to help in whatever way possible are recognized. Finally, my third committee member my URR committee member Dr. Carole Corcoran needs to be acknowledged for her review of my dissertation to ensure it met the highest of collegiate standings. Thank you to all of you, for without all of you this dissertation would not have been possible.

Finally, I must acknowledge the wonderful close relatives who volunteered to participate in this study. Your stories and your experiences were very touching and helped to produce a dissertation that values close relatives' perspectives in pediatric palliative care and can impact social change.

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Chapter 1: Introduction

Introduction

Childhood cancer is on the rise, with 12,400 children being diagnosed annually. Cancer is the most common cause of death by disease for children and adolescents in America (National Cancer Institute, 2005). Transition from life before cancer diagnosis to life after is often difficult for children and families (Harrington, Kimball, & Bean, 2009). A family's ability to cope is related to their ability to transition from the world before a cancer diagnosis to the world of cancer (Robinson, Carroll, & Watson, 2005). The diagnosis of pediatric cancer creates high levels of family conflict, and affects how parents view themselves and their families and friends, specifically during the first year after diagnosis (Pai, Lewandowksi, Youngstrom, Greenley, Drotar & Peterson, 2007). Families are faced with changes in social and family roles, changes in daily activities (Kazak, Simms, & Rourke, 2002) the burden of medical regimes (Bryant, 2003), and the fear of death. Families facing a pediatric cancer diagnosis may be at risk for higher levels of conflict (Pai et al., 2007). Support may help ease the burden of this traumatic and life-changing experience. Increased family support allows for expression of negative symptoms and feelings. The ability to express negative feelings creates a pathway for better adjustment (Fuemmeler, Brown, Williams, & Barredo, 2003).

Background of the Problem

Initially pediatric palliative care became a priority when the Initiative for Pediatric Palliative Care (IPPC) was established in 1998 as an education, research forum for pediatric palliative care. The IPPC recognized that the healthcare system was failing families and children who were faced with a life-threatening illness. The IPPC also recognized that as great strides were being made in adult palliative care, limited attention was focused on pediatric palliative care. At this point, the IPPC established the following objectives for hospitals:

- Maximize family involvement in decision making and care planning in the ways and to the degree that each family member finds comfortable;
- Inform children with life-threatening illnesses and involve them in decisions regarding their care and care planning as fully as possible, given their developmental abilities and desires;
- Reduce pain and distressful symptoms for children with life-threatening illnesses;
- Provide emotional and spiritual support to children and families as they cope with the multiple losses associated with life-threatening conditions;
- Facilitate the resolution of families' practical needs, such as the need for respite, through coordination with the community;
- Facilitate continuity of care across care settings, both within and outside the hospital, by providing each family with a designated care coordinator;
- Offer bereavement support to the child and the family before and after death (para.5).

The IPPC (2002) also stressed that in order to fulfill these objectives hospitals and related institutions must focus on:

- Developing explicit policies and procedures to advance the vision of humane family-centered care for children with life-threatening conditions; integrate palliative care with cure-oriented care from the beginning of the diagnosis forward so that it can benefit children who are gravely ill as well as those who are dying immediately;

> - Develop strategies for enhancing the palliative care clinical competence of staff, including skills in pain and symptom management, communication, and ethical analysis;
> - Develop specific routine mechanisms for meeting each of the child and families goals stated above; and commit to measuring the institutions progress towards these goals through routine, periodic data collection (para. 6).

> In addition to the IPPC's guidelines and recommendations for pediatric palliative care the American Academy of Pediatrics (AAP, 2000) also recommended that pediatric palliative care- based services utilizing the best guidelines and standards for children be developed and implemented. The AAP recommends the following minimum standards: "1) at least one consistent caregiver; 2) availability of an expert pediatric palliative care assistance 24 hours a day, 356 days a year; and 3) the availability of an interdisciplinary care team with sufficient expertise to address the physical, psychosocial, emotional, and spiritual needs of the child and family" (p. 355).

Studies have shown that children often suffer from pain and other symptoms, families often feel abandoned and overwhelmed for years to come, social support to families and children are often inadequate, and healthcare professionals are often unsupported and untrained for their work (Galloway & Yaster, 2000; Sahler, Frager, Levetown, Cohn, & Lipson, 2000; Wolfe et al., 2000). Since the initiation of the IPPC (2002) a surge has occurred in developing effective pediatric palliative care programming. This overwhelming growth in palliative care services for children has led to increased research into how best implement pediatric palliative care programs that will meet the needs of the child and their families; understand the perspectives of children, siblings, parents, and the healthcare professionals; utilize theories to explain how families cope with this traumatic experience; and what healthcare professionals can do to improve communication, programming, and services to address the needs of these families (Davies et al., 2008; Feudtner, 2007; Hewitt-Taylor, 2005).

Additionally, several studies have sought to examine the perspectives, coping, and adaptation of healthcare professionals, parents, siblings, and the child in palliative care (Labay & Walco, 2004; Sandgren, Thuleius, Fridlund, & Petersson, 2006; Yeh, Lee, Chen, Li, 2010). To date no studies have been conducted that identify the perspectives and experiences of close relatives involved in the pediatric palliative care process. As recently as 2009, the World Health Organization determined that palliative care encompasses meeting the entire individual and family needs including spiritual, emotional, and physical. Although attempts have been made to understand the experience of parents and siblings in the pediatric palliative care process, no research has examined the reactions and needs of the close relatives of these families specifically the grandparents, aunts and uncles of the child during the palliative care process.

Statement of the Problem

A child’s cancer diagnosis, treatment, and palliative care through bereavement are distressing times for the child and the family (Bradshaw, Hinds, Lansing, Gattus, & Razzouk, 2005; Harrington, Kimball, & Bean, 2009; Pai, Lewandowski, Youngstrom, Greenley, Drotar, & Peterson, 2007; Wolfe et al., 2000). The stress of this situation not only affects the child and the parents, but the entire family system (Patterson, Holm, & Gurney, 2004). Little research has been conducted that looked specifically at the relatives of these families, particularly the grandparents, aunts, and uncles. The Initiative for Pediatric Palliative Care (IPPC, 1998) American Academy of Pediatrics (AAP, 2000) Institute of Medicine (IOM, 2002) and the World Health Organization (WHO, 2009) have stressed the importance of pediatric care involving the child and the family, including close relatives. However, although these organizations have agreed that including the entire family in the process is a priority for high quality pediatric palliative care, no research with relatives in pediatric palliative care currently exists. Relatives who are called on to support the child and their parents during this difficult time must have a voice in order to provide services that will help them be better caregivers to those who need them (Gerhard et al., 2007; Hoekstra-Weebers, Jaspers, Kamps and Klip, 2001; Knapp & Contro, 2009). High levels of family support have been associated with decreasing the risks of repressing feelings and improving adjustment of families (McMenamy & Perrin, 2003).

Many studies have examined the impact of a cancer diagnosis on parents and siblings (Gerhardt et al., 2007; Labay & Walco, 2004; McMenamy & Perrin, 2003). Limited research exists that has identified close relatives' such as grandparents, aunts, and uncles' experiences of pediatric palliative care. Currently, no theory explains how grandparents, aunts, and uncles interpret their phenomenological experience and how the pediatric palliative care process affects them. For example, the healthcare arena needs to look at the ways in which close relatives are valued in the pediatric palliative care system, the ways in which close relatives experience pediatric palliative care, and the levels of support and meanings of their experiences that they identify as important. The gap presented in the literature needs to be reduced. This study attempted to fill this gap by generating a theory that explains the process that close relatives undertake while living through pediatric palliative care and the supportive measures they need to effectively cope. This theory provided a foundation to future research that will improve healthcare programming for close relatives and continue to provide evidence for pediatric palliative care as a national priority (WHO, 2009).

Purpose of the Study

The purpose of this study was to generate a substantive theory that explains how grandparents, aunts, and uncles of a child with cancer experience pediatric palliative care. The focus was on how these relatives experience pediatric palliative care and how they cope with the uncertainty and provide support to their family members who need them. This study laid the groundwork for in-depth future studies that could use this theory to examine issues that surround close relatives of a child in pediatric palliative care.

Conceptual Framework

Researchers have generated several theoretical models to understand the impact of pediatric palliative care. However, no theoretical model exists to explain how close relatives experience the pediatric palliative care process. Grounded theory is a qualitative approach in which the researcher generates a general, abstract theory of a process, action, or interaction derived from the data obtained from the participants (Creswell, 2009). Grounded theory approaches are often used when no theory exists to explain how individuals are experiencing a phenomenon (Creswell, 2007). The two primary approaches to grounded theory research are the systematic procedures developed by Strauss and Corbin (1990, 1998) and the constructivist approach of Charmaz (2005, 2006). The approach used in this study will be the constructivist approach of Charmaz (2005, 2006).

Recently, the focus has been on understanding how this process impacts the child, the siblings, and the parents (Bluebond-Langner, Belasco, Goldman, & Belasco, 2007; Labay & Walco, 2004; Sourkes, 2007). The family systems theory suggests that when one member of a family is impacted, the entire family system is impacted (Beckett, 2000). Impact of pediatric care has been viewed through stress and coping models (Vrijomet-Wiersma, van Klink, Kolk, Koopman, Ball, and Egeler, 2008) family systems models (Beckett, 2000) social support models (Trask et al., 2003; Widger, Steele, Oberle, & Davies, 2009) and hope theory (Reeder & Serwint, 2009).

Nature of the Study

I employed a grounded theory as the qualitative methodology for this study. Creswell (2007) suggested using a qualitative study design when problems or issues need to be explored. Qualitative research seeks to understand participants' perspectives and the meanings associated with these perspectives (Charmaz, 2005). I developed a substantive-level theory based on the perceptions of close relatives and how they are impacted by their experience of pediatric palliative care.

After obtaining approval from the Walden University Instructional Review Board (IRB # 12-22-10-0142113) and consent I conducted semi-structured interviews with nine participants. The participants were referred from a palliative care organization in the Midwest. When this population failed to illicit enough volunteers, the researcher went back to the IRB to get approval to use a snowball sample. Permission was granted under the same IRB number. The participants were adults age 18 years or older and were selected based on eligibility criteria, and willingness to participate. The parents of the child and the close relatives were presented with informed consent, the purpose and means of the study, and confidentiality practices of the researcher. The participants were asked to consent to a semi-structured audio-recorded face-to-face interview in a setting outside of their home (a requirement put in place by the IRB). Participants were asked to respond to two questions in journal format. In addition to writing in the journals, participants were encouraged to draw pictures use photographs or be creative by any means in their journals.

The journals were given to the participants with a self-addressed envelope and the researcher requested them to be returned within one week.

After all data had been collected qualitative analysis was used to interpret the interviews and the journal entries. Several techniques were employed to ensure that this study is authentic, reliable and valid including: spending ample time in the field collecting data, building rapport with the participants in order to establish trust in the relationship and using inter-rater reliability procedures (Schensul & LeCompte, 1999). Reliability in qualitative research typically refers to the stability of multiple coders of the data sets or intercoder agreement (Creswell, 2007). Another peer from Walden University was used as a secondary coder. Other methods used to ensure reliability were documentation through memos and verbatim transcription of the interviews including pauses (Creswell, 2007).

The methods used to verify trustworthiness that were used in this study included: triangulation of data, incorporating the interview data from the participants, using observation data, member checking, journaling excerpts and the researcher's memos to develop themes present in the data (Lincoln & Guba, 1985). Utilizing thick description by which the researcher writes narratives that present details, emotions, actions, and meanings of interactions with other family members and hospital personnel experienced by the participants (Charmaz, 2006) in addition to quoting the participants adds to the trustworthiness of the study. A more thorough detailed synopsis regarding methodology, data collection and data analysis techniques can be found in Chapter 3.

Research Questions

The primary research question for this study is:

> To what extent is pediatric palliative care meeting its objectives of family support through the provision of quality interaction forums (one-to-one and /or group) among close relatives?

Secondary questions are:

1. To what extent do close relatives in pediatric palliative care feel supported, understood, and valued through their involvement in pediatric palliative care?
2. To what extent is a close relative's experience of pediatric palliative care impacted through interactions with other family members and healthcare professionals?
3. To what extent is a close relative's experience of pediatric palliative care impacted by factors of hope, uncertainty, adaptation, stress, and coping?

Operational Definitions

The following terms are defined as they are used in this study.

Close relative: is defined as a person connected with another person by blood or affinity (Children's Act of 2004).

Experience: for the purpose of this study will be defined as the thoughts and feelings that along with sensations create the total of human consciousness (Klinger, 1978).

Grounded Theory is a qualitative strategy in which the researcher develops an abstract theory of a process, action, or interaction that is grounded in the data collected from the participants (Creswell, 2009).

Palliative Care for the purpose of this study is defined as treatment to support the child emotionally, physically, and spiritually from diagnosis through bereavement (World Health Organization, 2009).

Pediatric for the purpose of this study is defined as concerned with the health of infants, children, and adolescents (Kliegman, Behrman, Jenson, & Stanton, 2007).

Social Constructivism is based on the meanings participants give to their lives based on their interactions with others. Individuals develop meanings of their experiences and direct these meanings towards objects or things. The constructivist approach utilizes the researchers' views, while uncovering experiences that are hidden or embedded in the participants (Charmaz, 2006).

Purposive Sampling: a process used in qualitative grounded theory research, in which the researcher selects the sample to be used in the research based on their ability to contribute to the development of the theory (Creswell, 2007).

Assumptions and Limitations

This study encompasses the assumptions of grounded theory research. These assumptions include: 1) the data collected will result in the central phenomenon as viewed by the participants 2) the researcher's bias will not impede the participants perspectives; and 3) that the data from several participants will result in themes that generate a theory (Corbin & Strauss, 2008). To reflect the principles of constructivist grounded theory (Charmaz, 2006) the data collected from the participants yielded multiple realities of their experience and resulted in the complex views of their emotions, interactions, views, and experience of the central phenomenon. It also assumed that the participants provided honest accounts of their experience.

Limitations of this study are multiple. Missing information or presenting information to depict oneself in a more favorable light are factors that may be present in this study. For example, the participants may have been unwilling to divulge information that presented themselves in a negative manner. Another weakness of this study was the small sample size that limits the amount of data to be collected and results in less generalization of results. Additionally, the sample came from various locations and therefore cannot be generalized to one location or one hospital. Representation that incorporates race, gender, ethnicity, and cultural differences may be potentially limited in this study.

Significance of the Study

This study provided an increased understanding of nonparental or sibling relatives engaged in the pediatric palliative care process. Additionally, the results of this study laid the groundwork for extensive research in an area that is under represented in the current literature. Results of this study will be particularly beneficial to those who work in the healthcare arena and specifically in the area of pediatric cancer and palliative care. Identification of the family system as heavily impacted by a cancer diagnosis has been reviewed (Beckett, 2000; Houtzager et al., 2004; Kazak et al., 2003). Failure to focus on the close relatives as part of the family unit is a disservice to the families experiencing palliative care. Finally, I suggest that the results of this study be used for program development and a better understanding of the perspectives of the close relatives who are heavily impacted by their pediatric palliative care process.

Implications for Social Change

The implication for positive social change from this study is the increased understanding of the effect of pediatric palliative care on close relatives. This study may also lead to the development of intervention programming for nonparents to help them cope. Effective programming for the close relatives would allow for better support of the parents and siblings. It is hoped that further research in this area will also be generated from the results of this study.

Further research may include quantifying the close relatives' experiences, improving palliative care programs to meet the needs of close relatives, and identifying additional positive and negative factors that influence the experience of close relatives.

Summary and Organization of the Dissertation

Pediatric palliative care has recently become a priority in the healthcare system (AAP, 2000; ICCP, 1998; WHO, 2009). The focus of pediatric palliative care has been on implementing programming that meets the physical, spiritual, and emotional needs of the child and the family members (WHO, 2009). Although the developing bodies of pediatric palliative care guidelines have stressed the importance of including all family members including close relatives in the pediatric palliative care process, no research to date has investigated the close relatives' experience relative to pediatric palliative care. This chapter provided a rationale for conducting this study and an overview of the research literature that identified this study's potential for adding to the growing body of literature in pediatric palliative care. It identified the use of a grounded theory design to substantiate a theory to explain how close relatives in the Midwest experience pediatric palliative care. This chapter discussed the research questions, the qualitative nature of the study, conceptual framework and defined operational terms. The chapter addressed the assumptions of the study and limitations and delimitations were acknowledged. A description of the significance of the study in understanding close relatives experience of pediatric palliative care and its potential for providing evidence for programmatic changes in healthcare organizations was presented.

The second chapter will review research that has been conducted in the area of pediatric palliative care including the impact on the child, siblings, and parents. This chapter will also focus on the lack of research that has validated the role of the close relatives of these children with cancer in palliative care and further validate the need for this study. The chapter will conclude with a rationale for conducting a grounded theory study with close relatives of children with cancer in palliative care.

Chapter 3 will discuss the research methodology of grounded theory. It will provide information regarding the role of the researcher in the data collection and the analysis processes. It will also include information detailing the participants, the sample methods, and ethical procedures that will be utilized. Data collection procedures, analysis, and dissemination of the results will conclude this chapter.

Chapter 2: Literature Review

Introduction

The purpose of this chapter is to synthesize the literature to date regarding pediatric palliative care. Review of books and journal articles that have looked at various perspectives of this phenomenon will be included. This review will highlight methodologies explaining the process of pediatric palliative care and how it affects family members and healthcare professionals. Furthermore, this review will look at theoretical models that have attempted to explain this phenomenon from the perspectives of the child, the siblings, the parents, and the healthcare professionals.

The use of GoogleScholar, ProQuest Dissertations and Theses, PsychARTICLES, PsychBOOKS, PsychINFO, SAGEJOURNALSOnline, CINAHL, Medline, SagePremier2010, Ovid Nursing Journals and Academic Search Premiere databases were used to obtain articles that address pediatric palliative care. Search words that were used included: pediatric palliative care, palliative care and coping, palliative care and family members, pediatric cancer, grounded theory, supportive care in pediatric cancer, healthcare professionals in pediatric palliative care, uncertainty in pediatric palliative care, and coping and pediatric palliative care.

Growth in Pediatric Palliative Care

This study attempted to add to the growing literature in the pediatric palliative care field. Pediatric palliative care programs aim to focus on life, although dying is regarded as part of the natural process. Pediatric palliative care does not attempt to postpone or hasten death; rather it focuses on the psychological and spiritual aspects of care, offers a support system to help patients live as actively as possible, and offers a support system to help the families cope during the patient's illness and during their bereavement (Cannaerta, Dierck de Casterle, & Grypdonck, 2004).

Utilizing a grounded theory approach this study attempted to fill a gap that exists in the current literature regarding the perspectives of grandparents, aunts, and uncles of a child with cancer that is involved in the pediatric palliative care process. In the past 10 years pediatric palliative care has become a priority and, the American Academy of Pediatrics (AAP, 2000) recommended that pediatric palliative care based services utilizing the best guidelines and standards for children be developed and implemented. The AAP recommends the following minimum standards: "1) at least one consistent caregiver; 2) availability of an expert pediatric palliative care assistance 24 hours a day, 356 days a year; and 3) the availability of an interdisciplinary care team with sufficient expertise to address the physical, psychosocial, emotional, and spiritual needs of the child and family" (pg. 355). The team should include social workers, physicians, psychologists, nurses, spiritual advisors, and child life therapists. The AAP stresses the importance of providing the full range of pediatric services to all families regardless of need including a care coordinator, respite for family caregivers, and bereavement services for the family, caregivers, and all others affected by the death of the child. Additionally, the Institute of Medicine (IOM; 2002) argued that services for those with fatal or near fatal conditions is lacking and that more data and scientific knowledge is needed to improve palliative care. Furthermore, the Initiative for Pediatric Palliative Care (IPPC) established in 1998 recognized that the healthcare system was failing children and families who were faced with a life-threatening illness and identified program objectives and guidelines for hospitals and related institutions to follow in developing pediatric palliative care programs. The IPPC focus on pediatric palliative care was developed largely based on research that focused on the lack of pain and symptom management of the child with the life-threatening illness, feelings of abandonment by families, and lack of social support for families and healthcare professionals (Galloway & Yaster, 2000; Sahler et al., 2000; Wolfe, et al., 2000).

The World Health Organization (WHO, 2005) has stressed the importance of pediatric palliative care to all who work in this area of healthcare. The WHO has defined palliative care as " improving the quality of life of patients facing life-threatening illnesses, and their families, through the prevention and relief of suffering through early identification and treatment of pain and other problems, whether physical, psychosocial, or spiritual" (para. 1). Furthermore, the WHO reported that palliative care also involves giving support to the families. Palliative care begins at diagnosis and continues regardless if a child receives disease-directed treatment or not. Effective palliative care requires a broad multidisciplinary approach that includes the family and utilizes community resources if needed; and can be provided in several environments including the patients home, community health centers, or in tertiary-care facilities. This overwhelming growth in palliative care services for children has led to increased research into how best implement pediatric palliative care programs that will meet the needs of the child and their families; understand the perspectives of children, siblings, parents, and the healthcare professionals; to utilize theories to explain how families cope with this traumatic experience; and what healthcare professionals can do to improve communication, programming, and services to address the needs of these families (Davies Schring, Partridge, Cooper, Hughes, & Philp, 2008; Feudtner, 2007; Hewitt-Taylor, 2005).

Healthcare Perspectives

Providing palliative care to children can be challenging. The unknown progression of the disease, the family members fight to continue to search for a cure; and the lack of effective communication between staff members, patients and their families add to the frustration of service delivery (Davies, Schring, Partridge, Cooper, Hughes, & Philp, 2008). The focus of pediatric palliative care in the healthcare system is to focus on the quality of life of children with life-limiting illnesses and their families (Liben, Papadatou, & Wolfe, 2007). To be more effective in this area, the healthcare professionals have to develop better communication skills, increase their knowledge of palliative care in the pediatric arena, develop approaches that are multi-cultural, provide care that addresses suffering, improve strategies to address the healthcare provider and the caregivers, and most importantly understand the needs of the children and families (Mack, Hilden, Watterson, Moore, Turner, Grier, et al., 2005; Solomon & Browning; 2005). One of the most important findings regarding pediatric palliative care; is the relationship between the healthcare professionals and the families (Solomon & Browning). The quality of the relationship and the ability of the healthcare professional to manage the symptoms of the child while providing palliative measures is essential to the family feeling comfortable with the care they are receiving, even though death may be imminent (Solomon & Browning). Mack et al. (2005) surveyed parents and physicians to ascertain the assessment of the quality of care received. Most parents, (82%) believed that the quality of physician care towards the end of life was very good. The quality of the communication between the physician and the parent impacted the level of care assessed by the parent. The sensitivity of the physician in communicating difficult issues, being open and honest about what to expect towards the end-of-life, and adequately preparing the parents and the child when appropriate about what to expect in the final days, were all areas that parents rated as crucial in assessing quality of care.

Barriers to pediatric palliative care have been reviewed (Contro, Larson, Scofield, Sourkes, & Cohen, 2004, Davies et al., 2008; Hilden, Emmanuel, Fairclough, Link, Foley, Clarridge et al., 2001). Davies et al. (2008) surveyed 240 physicians, nurses, and other healthcare providers on their perceptions of barriers to families receiving palliative and end-of-life care services. They identified the following barriers: uncertainty in prognosis and differing treatment goals between physicians, nursing staff, and families, and barriers in communication as the primary barriers to children and family receiving the care that they need. A similar study conducted by Hilden et al. surveyed pediatric oncologists regarding their attitudes and practices regarding end-of-life care for children. They found similar barriers including: communication between physician and parents, adequate pain control, and decision-making. However, one difference they found was pediatric oncologists often felt inadequate in their knowledge and training in dealing with childhood death.

A similar study conducted by Contro et al. (2004) found that parents and staff members had similar views regarding palliative care. Their findings indicated that staff members generally felt inexperienced in communicating with families regarding palliative care, families often felt distress regarding the delivery of bad news, and staff members reported feeling inexperienced in their ability to manage pain and symptoms. Furthermore, both staff members and families shared a need for more support.

Parents' Perspectives

Parents who have a child with a life-threatening illness, such as cancer, are experiencing a tragedy. From the moment of diagnosis, through the many treatment modalities, until remission or death, a parent is consumed with his or her child's illness, treatment, and finding a cure. The interaction between the child's healthcare staff, the child, and the family is vital to the parents' beliefs, that care for their child is acceptable and responsive (Mack et al., 2005). Open, honest communication with the healthcare staff appears to be one attribute in which parents measure positive experiences of palliative care (Solomon & Browning, 2005). Additional measures of positive experiences of palliative care involve managing of the child's pain and symptoms, supportive healthcare staff, and an understanding for the parents' need to never lose hope (Bluebond-Langner, Belasco, Goldman, & Belasco, 2007). For parents the perspective of cancer-directed care and symptom-directed care are interchangeable (Bluebond et al. 2007). Parents tend to want to search beyond the limits imposed upon them by the oncologist, to engage in cancer-directed and cancer-symptom care simultaneously, and to be primarily responsible for the decisions that affect their child's treatment and quality of life (Bluebond et al.). Contradictory to this study regarding a parents' need to be heavily involved in decision-making is a grounded theory study conducted by Carnevale et al. (2006) in France, where the parents' wanted the responsibility of the life-support decisions regarding their children to lie in the hands of the physicians. However, similar to other studies previously reviewed better parent communication training was a primary factor in the care of critically ill children for families in France.

A more recent study conducted in Australia by Monterosso, Kristjanson, and Phillips (2009) found that parents required honest and open communication throughout their child's disease trajectory and in to palliative and supportive care. Furthermore, the 69 parents interviewed wanted the opportunity to care for their child at home with family, close relatives, and friends providing support. Parents that participated in this study were eager to share their stories regarding their child's illness and death, and were hopeful that their experiences would lead to improvements in the care of children with cancer, and their families.

The stress of caring for a child with a fatal disease is incomprehensible. Parents are faced with challenges in ensuring that their child's pain is managed, their psychological and spiritual needs are being met, and their quality of life is maintained until death. These burdens add to the parents' emotional suffering. Additionally, while the child's physical needs are often met the psychological symptoms of children and parents are often overlooked (Theunissen, Hoogerbrugge, Achterberg, Vernooij-Dassen, & van den Ende, 2006). Preparing parents for the loss of their child is an insurmountable task. Understanding the major factors that affect parents as they prepare for the death of their child is vital to addressing their needs. Kreichbergs, Valdimarsdottir, Onelov, Bjork, Steineck, and Henter (2005) found that the inability to alleviate the physical pain of a child near death and a difficult moment of death affected parents years after the child's death. These findings suggest that children with cancer involved in palliative and end-of-life care may be suffering more than is recognized, and that the parent's inability to alleviate the pain and difficulties at death creates long-term emotional turmoil.

Siblings' Perspectives

When a child is diagnosed with cancer, the impact of the disease affects the entire family. Siblings are no exception. Adjustment problems, insecurity, and anxiety are factors found in children with a sibling who has cancer. Houtzager, Oort, Hoekstra-Weebers, Caron, Grootenhuis, and Last (2004) conducted a study with 83 siblings aged 7-19. They found that siblings are most affected by the illness shortly after diagnosis and gradually learn to adapt. Additionally, siblings with adjustment problems were older, female and had family systems that were highly adaptable. This longitudinal study investigated siblings' adjustment at one, six, 12, and 24 months after diagnosis. Results of this study suggest that longitudinal studies of sibling adjustment may be more reflective of adjustment than cross-sectional studies that evaluate a sibling's response at one point in time. For example, Alderfer, Labay and Kazak (2003) found that 30% of 99 siblings of cancer survivors exhibited posttraumatic stress symptoms.

The Child's Perspective

Childhood cancer presents with an uncertainty that the child must be engaged in to manage the illness (Stewart, 2003). The uncertainty in these children allows them to develop a "getting used to it" attitude that helps them to focus on ordinary parts of their lives (Stewart, 2003, p.398). The process by which children view their treatment as routine and their lives as no different than any other peer is an important process for the child to see themselves as normal (Stewart, 2003).

The immediate and long-term effects of cancer have long been seen as detrimental to the psychological, emotional, and physical well-being of these children (Patenaude & Kupst, 2005). Transition from life before cancer to life after diagnosis is often difficult for children and families to grasp (Harrington, Kimball, & Bean, 2009). The age of the child at time of diagnosis appears to play a major role in the well-being of the child. Earle and Eiser (2007) looked at the adjustment of children during the two to three years of undergoing treatment for acute lymphoblastic leukemia (ALL). They found that children in the youngest group, with a mean age of 3.6 years of age were well adjusted including adjusting quickly to going to the hospital, taking medications, and going through painful procedures. This was attributed to their inability to fully understand what was happening which became a major factor in their adjustment. The children age 5-9 years had some adjustment issues related to social problems and appearance concerns. The group that had the least amount of adjustment was the group of children aged 10-14. This group as expected was overly concerned with the need to look the same and be like their peers. In contrast, Ferguson and Hendricks (2008) evaluated the effects of hope and well-being in adolescents' age 13-21 years with cancer. They found that adolescents reported higher levels of spiritual well-being, religious well-being, and existential well-being than children with cancer at different periods of their lives. One possible explanation for this may be the elapsed time since diagnosis.

Due to the severity of childhood cancer, understanding the disease is crucial to coping with it (Bares & Gelman, 2008). Children at various developmental stages grasp different aspects of the disease. Younger children often see no difference between cancer and a common cold. Elementary-aged children begin to grasp some of the differences, and older adolescents into adults have the greatest understanding (Bares & Gelman, 2008).

Psychological effects of cancer on children and adolescents can be both negative and positive. Treatment has been found to be most difficult on adolescents (Parry & Chesler, 2005). Identifying a positive or hopeful attitude as a coping strategy has increased adolescents' psychosocial adjustment (Parry & Chesler, 2005). Often times, children coping with this disease use repression adaptation which may positively bias their reports of self-adjustment (McMenamy & Perrin, 2003). Children with cancer have shown higher levels of repressive adaptation style than children with other chronic diseases and healthy children (Phipps, Steele, Hall, & Leigh, 2001). Furthermore, children who report that they are coping with their illness and report minimal concerns or worries may not be experiencing minimal distress (Fuemmeler, Brown, Williams, & Barredo, 2003). Children experiencing pain also report psychological negative symptoms including feelings of anxiety and depression (Blouent, Piira, Cohen, & Cheng, 2006).

The impact of physical, social, and emotional stressors on a child with cancer can be profound. In addition to these factors, the impact of diagnosis and treatment of cancer can also affect academic achievement. Adverse effects of treatment can affect high-order cognitive skills and academic achievement (Daley, Kral, & Brown, 2008).

When a child's death is impending, those that understand the death process want their wishes to be followed. Adolescents specifically, are fully aware of their impending death and have firm beliefs in what and how they want the process to come to an end (Bares & Gellman, 2008). Younger children appear to be filled with more ambivalence due to their limited understanding of the death process (Earle & Eiser, 2007).

Emotional Disclosure

The concept of emotional disclosure was developed by Pennebraker and Beall (1986). This process requires individuals to write or speak about their deepest thoughts and feelings regarding stressful experiences. It has been used with various populations to reduce stress, decrease physical and psychological symptoms, and improve adjustment and well-being (Stanton, Danuff-Burg, Sworowski, Collins, Bvanstetter, Rodriguez-Hanley, et al., 2002). Written emotional disclosure has been used with some cancer populations including breast cancer patients, and caregivers of chronically ill children (Cepeda et al., 2008; Schwartz & Drotar, 2004; Zakowski, Ramati, Morton, Johnson, & Flanigan, 2004). Positive effects of written emotional disclosure have been found in these populations (Stanton et al., Zakowski et al.).

A study by Stanton and colleagues (2002) with breast cancer patients found that emotional disclosure reduced physical symptoms and increased positive psychological adjustment in patients that did not engage in avoidance techniques. Similarly, a study with cancer patients in general found that emotional disclosure reduced distress and buffered the effects of negative response to their cancer at a 6 month follow-up (Zakowski et al. 2004).

A more recent randomized, single-blind controlled trial with adult cancer patients (Cepeda et al., 2008) sought to investigate the incorporation of a narrative approach to reduce physical and psychological symptoms associated with cancer. Results indicated that patients that demonstrated high emotional disclosure reported significantly less pain, and improved well-being compared to those patients that disclosed less emotional material. Emotional disclosure appears to be most effective when disclosure is high, a location that is solitary, and when both positive and negative thoughts and feelings are expressed.

Contrary to these previous studies in which emotional disclosure was beneficial, a study investigating caregivers of children with chronic illnesses including, cancer and sickle-cell disease using the emotional disclosure technique found that the group that wrote about traumas and stressors experienced fewer positive effects than a control group that wrote about summer activities (Schwartz & Drotar, 2004). Speculation as to why this was the case include a small sample size, the fact that the data was collected in a pediatric hospital in which there are many distractions and parents were not able to disguise the stressful-response to the writing task. Furthermore, it was the parents of patients completing the writing task instead of the patients themselves.

Theories Used by Previous Researchers

Theories used by previous researchers to explain how children, siblings, and parents cope with the palliative care process have utilized uncertainty, hope, adaptation, stress and coping, and family support as models for their research. The following segments describe how theories have driven the investigation into cancer diagnosis, treatment, and pediatric palliative care.

Uncertainty Theory

Uncertainty as defined by Mishel (1988a) is the inability to understand the meaning of illness-related events, in which the decision maker is unable to assign definitive values to objects and events or is unable to predict outcomes due to limited information. The diagnosis of a child with cancer will undoubtedly lead to uncertainty in treatment effectiveness, survival, normal routines, family functioning, and ability to adapt. Santacroce (2002) investigated the relationship between uncertainty, anxiety, and symptoms of posttraumatic stress in parents of children newly diagnosed with cancer. The study guided by the uncertainty in illness theory (Mishel) found that a significant relationship between anxiety and posttraumatic stress symptoms. Furthermore, as expected the anxiety levels were higher in parents of children recently diagnosed than parents of childhood survivors. Surprising to the researchers was the fact that the level of uncertainty was lower than expected. It would be expected that levels of uncertainty would be increased in parents who have a child with cancer. One would expect that parents in this situation would be filled with feelings of uncertainty, the uncertainty of the treatment and impact of the diagnosis on the family, the uncertainty of their ability to get their child through the traumatic experience, and the uncertainty of a cure. Uncertainty has been demonstrated at the highest levels by parents immediately upon completion of treatment (Stam, Grootenhuis, Brons, Caron, & Last, 2006).

Stress and Coping Theory

Lazarus (1993) suggested that coping is a process that changes over time and within situational contexts. Vrijomet-Wiersma, van Klink, Kolk, Koopman, Ball, and Egeler (2008) investigated a parents' response to their child's cancer diagnosis. The review of literature between 1997 and 2007, was based on Lazarus and Springer's (1984) stress and coping model in which the parents were presented with the stressor (diagnosis) which starts the process of appraising the stressor, followed by strain (pressure of demand of the stressor) which is later manifested in uncertainty, depressive symptoms, anxiety, and Posttraumatic Stress Syndrome. Their findings suggested that parental stress and how much time has elapsed after a child's diagnosis before the studies were conducted varies considerably which makes comparison of the studies impossible. The results suggest that emotional stress is most significant around the time of diagnosis. However, in some cases parents were still experiencing stressful symptoms 5 years after diagnosis. The review of these studies indicated that parental stress may not be definitive and may change over time and depending on the situation.

Adaptation Theory

A family's ability to adapt to the many demands of a cancer diagnosis impacts how the child and other family members will adjust to the negative consequences of the diagnosis. A qualitative analysis study conducted by Patterson, Holm, and Gurney (2004) used focus groups to investigate the coping behaviors parents found most helpful for their family in coping with their child's diagnosis. The results of this study mirrored other literature with respect to how the cancer experience affects families (Hoekstra-Weebers et al., 2001; Kazak et al., 2003; Trask et al., 2003). Using the Family Adjustment and Adaptation Response Model (Patterson, 1988) the parents identified their child's pain and illness as a major source of guilt, grief, helplessness, and feeling overwhelmed. Additionally, a major factor for these parents was the lack of support they received or hurtful and insensitive actions that they experienced from their loved ones. It seems that support from others was viewed as both a welcome relief, and a source of strain. However, when families were identifying resources, support from others was most frequently mentioned. Adolescents undergoing cancer treatment identified their parents as their greatest source of support (Trask, Paterson, Trask, Bares, Birt, & Maan, 2003). Trask et al. found that adolescents adapted to their diagnosis more readily when their family had strong ties, showed a great sense of support, and engaged in adaptive coping skills. Similarly, the impact of cancer on siblings was mediated by family cohesion and adaptability (Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 2006).

Phipps, Ric, Hall, and Leigh (2001) conducted a longitudinal study to determine whether repressive adaptation style in children with cancer was premorbid or reactive. The authors assessed the children at time of diagnosis, six months, and one year after diagnosis. The cancer group was compared to a group of healthy children as well as a group of children that had a chronic illness but of a nonmalignant source. They found that children with cancer at the time of diagnosis showed higher levels of repressive adaptive style then the group of healthy children and this level was maintained. Other findings suggest that children with chronic illness also showed levels of repressive adaptive style comparable to the cancer group.

Family members impacted by the diagnosis, treatment and long-term effects of this disease must find ways to adapt to their new roles and ever changing lives. Mothers often suffer the greatest impact because they are the primary caretakers and the most involved in their child's treatment. They are often responsible for staying with the child during hospital stays, getting them to their appointments, ensuring that their social, emotional, and physical needs are being met, as well as managing the other aspects of motherhood (Keene, 2002). Mothers and fathers of recently diagnosed children reported significantly higher amounts of distress than their normal counterparts (Pai, Lewandowski, Youngstrom, Greenley, Drotar, & Peterson, 2007). A family's ability to cope is related to their ability to transition from the world before cancer diagnosis to the world of cancer (Robinson, Carroll, & Watson, 2005).

The diagnosis of a pediatric cancer creates higher levels of family conflict and impacts how parents see themselves, their families, and friends specifically during the first year after diagnosis (Pai et al., 2007). Mothers reported the highest amount of distress, compared to fathers of a child with cancer, and parents who have healthy children (Pai et al.). Parents with a child with cancer have also been found to be resilient and function as well as parents with healthy children (Gerhardt, Gutzwiller, Hwiet, Fischer, Noll, & Vannetta, 2007). Additionally, these parents of a child with cancer reported more anxiety but more social support from their families and less family conflict (Gerhardt et al., 2007). High levels of family support have also been associated with decreasing the risks of repression on the adjustment of families (McMenamy & Perrin, 2003). Increased family support allows for expression of negative symptoms and feelings. The ability to use this coping technique creates a pathway for better adjustment (Fuemmeler, Brown, Williams, & Barredo, 2003).

Hope Theory

Snyder (2000) defined hope as having three main components involved in the element of hope: 1) the mindset that one can obtain future goals, 2) the ability to plan or develop roadmaps to achieve those goals, 3) perception of the individual as being capable of achieving goals. Hope in the palliative care process with children who have life-limiting illnesses often is what carries parents through the dreadful illness trajectory to a cure or to palliative and bereavement care. Parents often view themselves as bearers of hope, hope for a cure and hope for new life (Reeder & Serwint, 2009). When those around them have given up or realize that the end is near, as is often the case with the healthcare professionals who recognize that no there is no option for a cure, parents feel a strong urgency to keep the feeling of hope alive. Effective parental coping has been found to influence a child's sense of hope (Reeder & Serwint).

Parents dealing with their child's cancer diagnosis can often feel anxious and uncertain about the outcome. This anxiety and uncertainty can lead to hopelessness. Bayet, Erdem, and Kuzucu (2008) found that mothers have more feelings of hopelessness than fathers because of the amount of time they spend with their children. Most often, mothers quit their jobs and refrain from any social outings, which can increase their levels of anxiety and in turn lead to feelings of despair and hopelessness. In their study, trait anxiety and depression scores were higher in mothers and their social support level was lower than in fathers. However, anxiety and depressive scores were reduced when social support was enhanced. This finding suggests that mothers specifically require more social support during their child's illness and that healthcare programs should include this component when working with families and children with cancer.

Family Systems Model

The impact of childhood cancer and palliative care on a family is immense. Beckett (2000) suggested that when one member of a family is impacted by a stressor, all family members are impacted. A family's ability to adapt to the stressor impacts how a child and other family members will adjust (Kazak, 2002). Patterson et al. (2004) found that an entire family is impacted when a child has a cancer diagnosis. This impact has many negative effects including uncertainty, the strain of the diagnosis on the family, and the lack of support and insensitivity of family and friends.

Although it is clear that palliative care affects the entire family, extended family and community, there are still many unanswered questions. Knapp and Contro (2009) recently identified areas of pediatric palliative care that require more focus if in fact the entire family is going to be supported through diagnosis and into palliative care. They noted that although family supportive care is a priority, it is not clear what the priorities in providing this care are. Furthermore, they reported that much of the research regarding parents' needs has been conducted with bereaved parents. If palliative care is truly to be integrated with curative care, then further insight into the needs of these parents at diagnosis, through treatment, and into bereavement care is vital. Knapp and Contro also found limited research into fathers' and grandparents' perspectives. This information is required to ensure that interventions address their specific needs. Finally, little information exist that addresses how culture, language, and spirituality are utilized through the support of families.

Social Constructivism

Social constructivist principles suggest that meaning of experiences develop through our interaction with others (Creswell, 2007). Perceptions, understanding, and meaning that individuals give to their experiences are a major theoretical component (Charmaz, 2006) of social constructivism. Formulations of individual experiences generate a framework of meaning. Relevant to this proposed grounded theory study, is the inductive process of social constructivism by which a theory is generated to ascertain meaning (Charmaz, 2006). Theorists have recognized the importance of the subjective experiences of families involved in palliative care. Woodgate and Degner (2003) developed a substantive theory from the perspectives of the family focused on “keeping the spirit alive; the spirit within” (pg. 108). This study grounded in a constant comparative analysis sought to gain insight into how families perceived the cancer process. Bereaved processes of fathers were explored using grounded theory methods to understand the impact of a child’s death on fathers. The underlying theory developed encompassed battling with uncertainty, with responsibility, and with everyday disruption (Davies, Gudmundsdottir, Worden, Orloff, Sumner, & Brenner, 2004).

Theorists utilizing the theory of social constructivism have understood the importance of the subjective meanings that children, families, and healthcare professionals bring to the palliative care experience (Bluebond-Langner, et al., 2007; Carnevale et al., 2006). With the focus of palliative care on understanding the entire family unit; the use of constructivist principles appears to be justified. A more recent study investigated the needs of bereaved parents in a pediatric intensive care unit (Meert, Briller, Schim, Thruston, & Kabel, 2009). The researchers interviewed 33 parents or guardians of 26 children who had died in the pediatric intensive care unit. Meert et al. recognized the importance of gaining a deeper understanding of parents' needs through the use of qualitative analysis. Four themes emerged from the participants' accounts of people, places, events, interactions, and reflections on the meaning and significance. These themes included: who I am, while my child was dying, my child's death context, and my bereavement journey. Findings suggest that the cultural context of the Pediatric Intensive Care Unit shapes parental needs, specifically around the time of the child's death. Staff's ability to recognize cultural, religious practices and family traditions has a positive impact on the parent's bereavement process. Furthermore, the parents need to maintain connection with their child has led to increased emphasis on family-centered care. Parents need for bereavement support has improved the follow-up programs and memorial services. Finally, happenings that occur at the time of the child's final hospitalization produce memories that will either comfort or haunt the parents for years to come.

The advantage of the social constructivist theory is the reliance on the perspectives of the participants and a wide range of investigation. Additionally, the social constructivist approach is well suited for this study because it is based on the premise that meaning is created from one's experience (Charmaz, 2006). This proposed grounded theory study will utilize these frameworks in its design and analysis of pediatric palliative care.

Summary of the Review of Theories Relevant to this Study

Researchers have utilized many different theories to examine aspects of pediatric palliative care. The notion of family systems theory offers reasonable explanations as to how a family is impacted but its use in palliative care research has been limited. Adaptation theory has been widely researched to describe how parents and families have coped with the cancer process and suggests that families succumb to the distressing process and manage stressors as they develop. However, this theoretical framework has not investigated the close relatives' abilities to adapt. Hope, uncertainty, and support theories, although practical explanations of parents and children's mechanisms to describe palliative care are too narrowly focused to include close relatives. The lack of research into how close relatives utilize theories of hope, uncertainty, and support in pediatric palliative care is basically nonexistent.

Although not highly used, social constructivist theory offers the best explanation for understanding how close relatives construct meaning to their involvement in the pediatric palliative care process. The advantage of the social constructivist theory is the reliance on the perspectives of the participants and a wide range of investigation into how they assign meaning to their experience, perceive their experience, and function within that experience. This proposed study will utilize social constructivist theory in its design and analysis of pediatric palliative care.

Although many of these studies offer explanations of particular aspects of palliative care, a lack of coherent theory to explain close relatives' experiences exists. A theory is needed that offers a framework to understand the full range of experience, feelings, thoughts, and actions of close relatives in the cancer pediatric palliative care process. The social constructivist approach appears to provide a promising path to develop a theory that relies on the construction of one's experiences as the primary determinant of that experience.

Themes Appearing in the Literature

Support

Social support has long been viewed as an effective intervention to aid families undergoing stressful situations. The availability of others to rely on for help in times of need is a necessary component of most families getting through tough times. When a family is facing palliative care, this type of support becomes much more important. Families rely on others to help with errands, stay with siblings, do household chores, cook meals, listen when they need to talk, and just be there. Hoekstra-Weebers et al. (2001) found that parents received the most support at the time of diagnosis, but support diminished as time elapsed, and during the chronic stress of treatment, support was less than anticipated. Both mothers and fathers were dissatisfied with the support they received, and this created higher levels of psychological distress. It is apparent from this study that support measures for the family need to be more consistent and long-term. Supportive care however, does not just stop with immediate family members or close friends, but extends to the hospital personnel as well. The aim of recent research in palliative care is to identify a model that will ensure that families receive the highest quality of pediatric palliative care and that their individual and family needs will be met.

Widger, Steele, Oberle, and Davies (2009) investigated the parents' perspective of the support they received from hospital personnel. They specifically explored the quality of care during palliation, end-of-life and bereavement. Results indicated that the supportive care model fit well with the research and suggested that the highest quality of pediatric palliative care occurred when the child and family were valued and when families felt connected to the hospital personnel. This connection continued after the passing of the child, when families felt empowered and supported in their quest to find answers regarding their child's passing and when efforts were made to continue the bond with the family long after the child's death.

Pain

Pain is a central component of a cancer diagnosis. After children are born, parents attempt to protect them from both emotional and physical pain. When a child develops cancer, the need for parents to eliminate or reduce the amount of pain is an automatic response to their parental duty. Consequently, the reduction of pain has been sought by parents during every stage of cancer diagnosis through palliative care and the stage of dying. Kreichbergs et al (2005) found that parents were deeply affected by their child's unrelieved pain and that this memory continued in 57% of the families four to nine years after the death of their child.

Identifying pain in children towards the end of life continues to be an underdeveloped area (Wolfe et al., 2000). Recognizing pain caused by disease from that caused by treatment is an important element (Harris, 2004). This is most likely due to the limited amount of research in this area. The American Academy of Pediatrics (2000) has issued guidelines for the management of pain in palliative care. However, the focus of World Health Organization (2005) and International Association for the Study of Pain (2005) has been to look beyond the narrow focus of physical pain and implement procedures to address the coping skills of children and parents through the emotional and spiritual aspects of suffering.

Theunissen, Hoogerbrugge, van Achterberg, Prins, Veernooji-Dassen, and van den Ende (2006) conducted a study to collect a comprehensive understanding of the physical, psychological, and social symptoms of children with cancer and their parents during palliative care. The results indicated that 32 of 40 parents who responded reported a total of 202 physical symptoms their child experienced during the palliative phase. The most frequently reported physical symptoms were pain, poor appetite, fatigue, lack of mobility and vomiting. Also 175 psychological symptoms were reported including fear of death of the child, fear of physical problems of the child, and feelings of anger, somberness, and sadness.

Bereavement

Although survivor rates have increased for children with cancer there are children who relapse and cannot be cured. The death of a child presents with many unanswered questions, feelings of guilt and anger, and an enormous sense of loss to the parents. Mack, Hilden, Watterson, Grier, Weeks, & Wolfe (2004) utilized a survey to obtain information from parents with a child who had died. The results indicated that parents rated the overall care higher during their child's end-of-life stage when effective and compassionate communication from the physician was relayed, the physician showed sensitivity and compassion, prepared the family for the child's passing, and communicated with the child directly when needed.

Children at the end-of-life stage experience many distressing symptoms including fatigue, pain, and dyspnea (Wolfe, Grier, & Klor, 2000). These symptoms can be devastating to the family and management of these symptoms is imperative and on-going (Wolfe et al.). A child's inability to be cured is devastating and has an enormous impact on the family's hope that has been carrying them from the initial diagnosis, and through the treatment protocols (DeGraves & Aranda, 2005). A parent who loses his or her child has needs that must be met. Davies (2005) conducted interviews with 10 mothers regarding the loss of their child. The mothers said that time, space, and privacy with their dying child both before and after death were important in increasing their ability to cope. Furthermore, the grief of parents continued to include a need to preserve memories of their child and to recall events related to their child.

Some parents who have lost a child were able to adjust to the child's death and to use that experience in their everyday lives. It appears that these parents have found a balance through remembering their child and relieving their grief while engaging in a job and everyday responsibilities. Barrera et al. (2007) identified parents experiencing positive feelings during bereavement, overall adjustment, preparation for the loss of their child, and supportive social networks as factors that increased a parent's ability to cope with their child's death after six months. Barrera, O'Conner, D'Agostino, Spencer, Nicholas, and Jovcerska (2009) found consistent themes that were present in parents who had lost a child. These themes included: the loss of the child on their lives, wishing that their child could have enjoyed more while he or she was living, and feelings of grief surrounding the life experiences that their child will never take part in.

Survivorship

Cancer treatments have led to dramatic increases in survival rate of children and adolescents (Butler & Haser, 2006). For example, the cure rate of Acute Lymphoblastic Leukemia has risen to 90% (American Cancer Society, 2009). However, the long-term effects of cancer survivorship can be sought with mixed feelings of jubilation that the treatment is over, anxiety about what may come, and hope for the future (Cantrell & Conte, 2009). Parry and Chesler (2005) examined thriving as an element of cancer survivorship. Their findings suggest that coping, making meaning of their disease, and psychosocial/spiritual growth are related to long term psychosocial well-being and thriving. This sense of thriving or willingness to embrace life, living more fully, and embracing struggle helped with the healing process. In fact, survivors of childhood cancer have often been found to be similar in most areas of functioning as compared to adults who never had cancer (Robinson, Gerhardt, Vannetta, & Noll, 2009). Robinson et al. looked at the effects of family distress during the time when their child had cancer and the long-term effects of cancer on into young adulthood. Their findings suggest that in most areas of psychosocial functioning there is little difference between cancer survivors and their peers. However, they did find that parental distress at the initial time of diagnosis and young- adults' internalization of symptoms was related.

Survivors of childhood cancer are at increased risk for future health problems. Positive health behavior changes are associated with having more control over one's life, increased social supports, and making sense out of the meaning of life (Park, Edmondson, Fenster, & Blank, 2005). Children who have survived cancer will continue to be monitored for years after their diagnosis. This can create added stress to parents who fear that their child may relapse (Eiser, Eiser, & Greco, 2004). Eiser, et al. evaluated parents and their parenting style in relation to their child's quality of life during survivorship. Parents who promoted feelings of accomplishments and aspirations for their children experience greater parental well-being and their children reported greater quality of life than parents who used prevention methods concerned with safety and responsibility and were vigilant about fear and danger.

Communication

A recurrent theme in the literature pertaining to pediatric palliative care is communication. Quality of cancer treatment and palliative care has been related to a parent's perception of the communication skills of healthcare professionals. Parents report that honest, open, communication is vital to the assessment of the quality of care they receive (Mack et al., 2005). Furthermore, relationships with healthcare professionals were also found to be important (Hinds et al., 2005). Parents rated quality of care higher when information regarding end-of-life experiences was clear, sensitive techniques were used when relaying bad news, communication with the child was utilized when developmentally appropriate, and parents knew what to expect at the end-of-life (Mack et al., 2005). Similarly, a review of literature conducted by Lowey (2008) regarding specifically, the nurse-patient relationship, communication, and experience of dying, found that communication was most effective using a team approach and that caregivers wanted more effective communication and information regarding the end-of-life stage and dying.

Effective communication is a necessary component of good healthcare; however it is most often neglected in pediatric and pediatric subspecialty practice (Hilden et al., 2001). There appears to be some consensus that the field is focused on facts and figures, instead of developing rapport and relationships (Jurkovich, Pierce, Pananen, & Rivara, 2000). Furthermore, relaying difficult information to parents of children (Mack et al., 2005) and the use of trial and error in acquiring communication skills appear to be contributing attributes to effective communication in the healthcare setting (Hilden et al., 2001).

Monterosso et al. (2009) investigated the palliative needs of families in Australia whose child had died from cancer identified similar characteristics of families in the US. Australian families wanted improved clear and honest information about their child's diagnosis and prognosis, input from a multidisciplinary team regarding the care of their child at home, and more information and resources to manage their child's nutrition and pain.

The formulation of effective communication techniques is a skill that can be taught and can be learned (Feudtner, 2007; Leventown, 2008). One of the most valuable techniques healthcare professionals can utilize when communicating with parents and families is a warm and caring attitude (Heller & Solomon, 2005). The development of relationships with families during the illness trajectory through palliative care and bereavement is highly valued (Wright, 2008). Long after a child has been diagnosed, families still long for a relationship with their healthcare provider (D'Agostino, Berlin-Romalis, Jovcevska, & Barrera, 2007). Most often cancer families spend most of their time with healthcare professionals and, these relationships become vital to a family under distress.

Education of Healthcare Professionals

The primary focus of providing competent pediatric palliative care services to children and their families through educating healthcare professionals has seen a recent surge. Increasingly, a need has been identified to ensure that healthcare professionals feel competent in their abilities to meet the needs of children and families in palliative care. There is great concern from child oncologists that they lack the education and knowledge to implement palliative care into their curative care model and that there is a high reliance on trial and error with children who are dying (Hilden et al., 2001). Furthermore, pediatricians often fail to refer children for palliative care services (Thompson, Knapp, Madden, & Shenteman, 2009). Thompson et al. found that although referral for palliative care services should occur early in the course of the illness pediatricians identified palliative care services as similar to hospice and therefore forgo referral until curative therapies are no longer an option. Additionally, pediatric residents are not readily trained in pain and symptom management for those in palliative care (Kolavik, Walker, & Arnold, 2006). Nor are they readily trained in sensitive issues of death and dying.

To address these needs, a strong push to develop programming that will adequately train pediatric residents, nursing staff, and other healthcare professionals must be initiated. Improving awareness and education regarding the benefits of palliative care services for children are necessary among healthcare providers and to a greater extent the healthcare community at large (Knapp, 2009; Martin, 2006). The focus of this education must result in physicians and nurses increased knowledge of pediatric palliative care (Hewitt-Taylor, 2005) training on efficient communication techniques (Feudtner, 2007) and increased ability to discuss sensitive subjects such as palliative care, hospice, and bereavement (Contro et al., 2004). Attempts to increase the competency in healthcare professionals who work in the pediatric palliative care field is a necessary mandate. Competency in meeting the needs of all family members, including grandparents, aunts, and uncles involved in the pediatric care process is a necessary conquest. Furthermore, the importance of education focused around death and dying and the impact on the entire family has become a major focus in the healthcare field (Braund & Rose, 2001; Whittle, 2002).

A recent study conducted by Davies et al. (2008) sought to identify barriers perceived by pediatric providers to end-of-life care. This quantitative study surveyed nurses and physicians from an academic children's hospital in Western United States. The most common barriers reported included: uncertain prognosis, language barriers, time constraints, and family not ready to accept prognosis. Secondary factors included: barriers in communication, and lack of education in pain and palliative care. This study suggested that although strides are being made to improve the skills of healthcare providers in pediatric palliative care, competency is still lacking. Similarly, Hale, Long, Sanderson, and Carr (2008) sought to evaluate the educational preparation of nurses in the cancer and palliative care fields in England. Findings suggested that similar attributes are desired from parents and other healthcare professionals working in the field of cancer and palliative care. These attributes include: creating partnerships with children and their parents, effective clinical skills, collaborating with team members, and personal attributes that included nurses being viewed as "real people" (p. 16).

Review of Research Methodologies

Review of the literature surrounding methodologies used to investigate pediatric palliative care has revealed that quantitative studies have most often been used to understand the perspectives of healthcare professionals (Davies et al., 2008; Fowler, Poehling, Billheimer, Hamilton, Wu, Mulder, & Frangoul, 2006; & Mack et al., 2005) prepare residents for pediatric care, (Kolvarik et al., 2006) improve education practices for physicians, nurses, and other healthcare professionals (Braund & Rose, 2001; Hale et al., 2008), and identify the dimensions of pediatric palliative care programs (Arber, 2008). Conversely, qualitative studies have been used to understand the parents and child's needs (Bluebond-Langner et al., 2007; Ewing, 2008; Hinds et al., 2005), give siblings a voice (Wilkins & Woodgate, 2005), and describe the adaptation process of families in cancer and palliative care (Chao-Hsing et al., 2000; Parry, 2003; Patterson et al., 2004).

Specifically, grounded theory approaches have been utilized to substantiate meaning of particular groups within the palliative care process. For example, Woodgate and Degner (2003) sought to understand childhood cancer from the child's and the parents' perspectives. They conducted a longitudinal qualitative study using interpretive interactionism principles with 39 families in Canada. Data were analyzed using a constant comparative method of grounded theory and illness narratives. Since, the families could not separate their experiences of the cancer phenomenon from child versus family experience, a substantive theory of "keeping the spirit alive" (p.108) was developed. This theory made getting through the many rough spots of the cancer diagnosis easier.

Summary of Research on Pediatric Palliative Care

A review of relevant literature has been presented in this chapter. It began with a look at the definition of pediatric palliative care and emergence of research into the field. Perspectives of healthcare professionals, parents, child, and siblings have been reviewed. Prevalent theories that have been used in pediatric palliative care including: hope, uncertainty, adaptation, stress and coping, and family-systems theory were presented. Grounded theory research presented in pediatric palliative care sought to substantiate meaning for the child and the parents including capturing their experiences of palliative care and giving meaning to how and what they experienced. Additional themes that have played a major role in pediatric palliative care included: pain, support, bereavement, survivorship, communication, education of healthcare professionals, and journaling. The social constructivist viewpoint of Charmaz (2005, 2006) was presented as the basis for the conceptual framework of this study. Finally, the researcher presented a review of the research methods previously employed in pediatric palliative care research. The researcher adhered to a social constructivist paradigm by conducting a grounded theory study in order to develop a substantive theory about the effects of pediatric palliative care on close relatives.

The next chapter will define the research questions, and provide a rationale for the study. The role of the researcher, interviewer, and interpreter roles will be outlined. Furthermore, identification of potential conflicts of interest and biases will be explained. Additionally, context of the study, participants, data collection and data analysis techniques will be detailed. Finally, the chapter will conclude with a verification of authenticity and trustworthiness.

Chapter 3: Research Design

Introduction

The purpose of this qualitative study as outlined in Chapter 1 was the development of a substantive theory to explain how close relatives of children in pediatric palliative care define their experience. Theories used to explain how children, siblings, parents, and healthcare professionals interpret their experiences provide helpful information, but the theories: uncertainty, hope, and stress and coping, are limited in their generalization to close relatives. Family systems theory (Beckett, 2000) suggests that when one family member is affected, the entire system is affected. Although this theory presents strong evidence for how one defines his or her experience, its use typically is limited to the immediate family members, and does not extend to the close family members not living in the same household. As discussed in Chapter 2, uncertainty, hope, and stress and coping theories, although most likely components of close relatives' experiences with cancer and palliative care cannot fully explain the extent of how a close relative experiences pediatric palliative care.

By using a constructivist grounded theory design (Charmaz, 2006) this study expanded the knowledge of how close relatives experience pediatric palliative care, by seeking a richer understanding of how close relatives define their experience in palliative care. This study defined how they experience the pediatric palliative care process, events and people that are significant in their experience, how they cope with their feelings of uncertainty and anxiety while supporting their family members, how they view their role in the process, and what their needs are.

The primary question was: To what extent is pediatric palliative care meeting its objectives of family support through the provision of quality interaction forums (one-to-one and/or group) among close relatives?

Secondary questions include the following:

1. To what extent do close relatives in pediatric palliative care feel supported, understood and valued through their involvement in pediatric palliative care?
2. To what extent is a close relative's experience of pediatric palliative care impacted through interactions with other family members and healthcare professionals?
3. To what extent is a close relative's experience of pediatric palliative care impacted by factors of hope, uncertainty, adaptation, stress, and coping?

Rationale for Qualitative Methodology

This study used a qualitative research methodology. Creswell (2007) suggested using a qualitative study design when problems or issues need to be explored. Qualitative research occurs in the natural setting, analyzes information collected from the participants, and utilizes the researcher as the primary instrument to collect data. Qualitative research seeks to understand participants' perspectives and the meanings associated with these perspectives (Charmaz, 2005). In contrast, quantitative research seeks to compare variables and utilizes statistical data (Creswell, 2009). Although, they explore problems and issues, quantitative researchers are concerned with showing a statistical significant difference between variables (Creswell).

Qualitative studies seek to construct an understanding of experience through the gathering of rich, detailed descriptive data. Quantitative research utilizes close-ended questions, and predetermined approaches (Creswell, 2007). In qualitative studies, the researcher is vital to the research design and his or her role is clearly defined (Charmaz, 2005). When a researcher becomes the instrument in a design, the researcher is close to the participants and gains a deeper understanding of their experience (Creswell, 2007). In contrast, the researcher's role is less pivotal in quantitative research (Creswell, 2009).

The naturalistic environment where qualitative data is collected allows for collection of nuance of the experience (Creswell, 2007). Qualitative research with its dedication to collection of deep, rich data allows researchers to gain a vivid picture of the phenomenon experienced by the participants. Creswell suggested that qualitative research questions uncover how one assigns meaning to his or her experiences, what behaviors occur and in what context, and what theoretical approach best explains the phenomenon. For this study, understanding the phenomenon of close relatives and their experience of pediatric palliative care will help healthcare professionals to focus on their needs.

Constructivist Grounded Theory

The qualitative approach that was used for this research study was grounded theory that originated with Glaser and Corbin (1967). In this approach, the researcher seeks to develop a theory to explain an action, a process, or an interaction that utilizes multiple perspectives and follows a postmodern approach (Creswell, 2007). This study developed a theory based on the participants' own reported experiences. Grounded theory is a qualitative research design that enables the researcher to use methods that are systematic, but allow for flexibility with collection and analysis of the data. Through this approach theories can be constructed that are grounded in the data (Charmaz, 2006). Researchers utilizing grounded theory attempt to become part of and understand what their participants' lives are like. They look to understand the words and actions of their participants and then seek to make sense of the data (Charmaz).

The use of grounded theory for this study was chosen over other approaches primarily to generate an explanation of close relatives' experience in the pediatric palliative care process and to gain a better understanding of this phenomenon. A case study or narrative approach would be too limited for this study due to the small sample size. Phenomenological research has been conducted in this field with parents of children with cancer (Davies, 2005). Phenomenological approaches seek to understand the "lived" experiences of the individuals (Moustakas, 1994), they do not generate theories. A theory is needed to explain the phenomenon that close relatives' experience in the palliative care process. Ethnography was not chosen as the research methodology due to the likelihood that participants will come from various cultural groups. Ethnography is often used to describe and interpret the shared patterns of a culture-sharing group (Creswell, 2007). Grounded theory methods study the world through an open-ended approach and add systematic guidelines into the data collection and analysis (Charmaz, 2006).

In keeping with the process-orientation of grounded theory research, a theoretical sample was used. Theoretical sampling is used when participants are selected based on the ability to form a theory (Creswell, 2007). As an understanding of the close relatives' experiences unfolded new concepts were collected. Flexibility to adjust questions to allow for new concepts and interpretation of these concepts with new participants is a general component of grounded theory research (Charmaz, 2006).

Srauss and Corbin (1994) suggested utilizing open-ended questions to conduct interviews that are systematic, but also allow for flexibility to generate themes related to the theory. Intensive interviewing will be utilized for this study. This type of interviewing allows the researcher to elicit how the participant interpreted his or her experience (Charmaz, 2006). Journaling has been used as a research tool with various groups of individuals with cancer. It has been useful in eliciting valuable data regarding experiences and feelings (Cepeda et al., 2008; Schwartz & Drotar, 2004; Stanton et al., 2002). For example, Stanton et al. have shown that individuals with breast cancer found this type of journaling effective in reducing physical symptoms and improving psychological adjustment.

Role of the Researcher

The researcher is the primary instrument used in data collection for qualitative research (Creswell, 2007). My primary goal was to design a study in which the participants felt comfortable sharing their thoughts and feelings. As the primary instrument for this study, it is important that I was cognizant of the biases I brought to the research and share these biases with the readers. These biases are addressed later in the chapter. The purpose of the interview questions is to obtain information to answer the primary research questions and to identify through analysis a theory that describes the process close relatives experience in palliative care. In order to add to the richness and depth of the study, the researcher took extensive memos throughout the research study. These memos served as reflection of the researcher's thoughts, and participants' nonverbal behaviors throughout the interview process (Creswell, 2007).

Interviewer and Interpreter Roles

My role in this study was interviewer and interpreter. The combination of these roles allowed me to take notice of themes as they were presented by participants, and then expand the questioning process to gain a deeper understanding of the process. As suggested by Charmaz (2005) this type of interaction between the researcher and the participants leads to theorizing. Charmaz (2005) stresses the importance of the researcher incorporating one's own perspectives into the interview process. Additionally, researchers utilizing grounded study designs document observations of their participants (Creswell, 2007). Another role of the interviewer/interpreter in the social constructivist perspective is to pose open-ended questions that allowed for the perspectives of close relatives to be obtained (Maxwell, 2005). Allowing for perspectives of close relatives to be shared increases the likelihood that important elements in the formulation of the theory will not be missed (Charmaz, 2006).

Potential Conflicts and Biases

There were no potential conflicts with the approval of this study from the IRB or the cooperative agency. I did not have any ties to the agency chosen for study participants. The potential bias that exists is based on my personal experience. I had a son who had cancer and was in palliative care and later passed away. I was aware of how this bias may impact the study and I was cognizant of this bias throughout the study so as to prevent invalidity. I utilized another individual to code the text passages to ensure reasonable agreement among the coders (Creswell, 2007).

Methodology

Context of the Study

The study took place partially through a hospice organization in a major metropolitan area in Missouri and through a snowball sample in the Midwest. A letter of cooperation with this organization was obtained (see Appendix A). After recruiting participants and obtaining consent (see Appendix C, see Appendix E) participants were interviewed and asked to respond to two journal entries in addition to drawing or creating images using photographs or memorabilia in their journals. The interviews took place at coffee shops or offices of the participants. IRB approval (12-22-10-0142113) from Walden University was obtained before collecting the data.

The hospice organization serves children and adults providing palliative and end-of-life care services to patients and their families. They offer 24 hour assistance, pain management, assistance with school participation, collaboration with physician and other healthcare providers, counseling and support to help the family cope, monitoring the child's illness, spiritual support, and planning for future needs. They have been providing hospice and palliative care services since 1980. They annually serve over 2,000 families in nine counties.

Procedures

Selection of Participants

I obtained IRB approval (12-22-10-0142113) from Walden University before pursuing participants and collecting the data. The scope of the study and requirements of participants were fully explained. I obtained all consent forms from participants before collecting data. I completed the design of the study; interviewed the participants, interpreted and analyzed the data, and interpreted and presented results.. Finally, I disseminated findings to all interested parties.

Eligibility criteria for this study was participants over the age of 18, who were a grandparent, aunt, or uncle to a child who has cancer and is receiving pediatric palliative care services or has received pediatric palliative care services. A purposive sample, a non-probability means of sampling, in which the participants were chosen based on the eligibility criteria were utilized for this study (Creswell, 2007). The sample will consisted of 9 close relative participants and 8 parent participants. Creswell (2007) suggested that 15 to 20 interviews is sufficient to develop a theoretical framework or until saturation is reached; the point when no new information can be found.

The participants were invited to participate in the study by staff members of the organization. An information sheet that briefly outlines the study was given to the parents of the child (see Appendix B). The parents of the child consented to responding to one interview question in order to triangulate the data and provided contact information of their close relatives (see Appendix C). The close relatives were then contacted and were given a description of the study (see Appendix D). The close relatives were asked to participate through an informed consent (see Appendix E).

Ethical Considerations

I obtained written approval from the IRB before recruiting participants and collecting data. Approval was followed up with discussions with the administrators regarding the procedures and ethical considerations for the participants. Consent forms were shared with the administrators for approval (see Appendix C, Appendix E).

All potential parents of the children and the close relatives chosen to participate were provided with the purpose of the study, the role of the researcher, and the expectations of the participants. These expectations included taking part in a 1-hour audio-recorded interview responding to questions concerning the pediatric palliative care process. Additionally, the participants were asked to document in journal format responses to two open-ended interview questions. The participants were asked to draw or be creative in any way in their journals. I requested that the responses be returned to me within 7 days. The participants were informed of their ability to refrain from responding to certain questions, to reschedule their interview for another day, and to refrain from participation of the study at any time without penalty.

I informed participants of the possible benefits and risks to them through their participation. The potential benefits were their opportunity to share their experience of the pediatric palliative care process and to add to our existing knowledge. The potential risk was that they may experience distress at times throughout the interview process. This potential risk was addressed by providing a list of counselors they can contact (see Appendix K).

Participants and parents were informed that all information will be kept private and confidential. A written consent form outlining this information was obtained (see Appendix C, Appendix E). The form included information on how to contact the researcher or the dissertation chairperson to answer any questions or discuss concerns. A copy was given to participants.

Confidentiality was assured by conducting interviews in private locations. The audio-recording was kept with me at all times and was locked in a security cabinet in my home. When the information was uploaded for analysis it was password protected with only I knowing the password. Participants' names were not used on any transcription notes or reports and no other identifying information was utilized. I transcribed all interviews. The journal documentation was identified through a numerical system that only I had access too.

Data Collection Techniques

Interviews are the primary method for collection of data in grounded theory research (Creswell, 2007). For this study, semi-structured interviews were conducted in a location familiar with the participants. The semi-structured format allows for the combination of open-ended questions and the ability to seek clarification and generate hypotheses throughout the interview process (Schensul & LeCompte, 1999). Additionally, journal responses to two interview questions were collected. This approach allowed data to be collected by multiple methods. I conducted all interviews using a digital audio-recorder, so that all files could be uploaded for analysis. The interview questions included the following:

1.) What thoughts and feelings about your child, nephew, niece or grandchild did you have during the palliative care process?

Follow-up: How would you describe your relationship with your child, niece, nephew or grandchild during this time?

Follow-up: What people do you remember as being important to you during this time?

2.) What was the most difficult part of being in the palliative care process?

Follow-up: What important events do you remember about your experience?

3.) What persons or places do you remember as being significant during this time?

Follow-up: How did these persons or places help you cope during this difficult time?

The journal entry questions will include the following:

4.) What have you learned from the pediatric palliative care process?

5.) What do you think are the most important things I should know about your experience of palliative care?

An interview protocol was used during the interview (see Appendix F). The protocol contained an introduction page, followed by the interview questions. Two interview questions were listed per page, to allow space for follow-up questions and notes regarding nonverbal observations. The introduction page contained an overview of the study, consent procedures and confidentiality measures including options for withdrawal from the study. The two journal questions were provided to the participants in a journal (see Appendix G). They were asked to write their responses, in addition to using drawings or other creative ways to present information. The nature of this study was to generate a theory, and as such requires the flexibility to go back into the field and ask more questions as the data reveals itself (Charmaz, 2006). Therefore, other interview questions were asked of the participants as the theory emerged.

Data Analysis Techniques

Researchers utilizing grounded theory studies analyze the data after the interview process (Creswell, 2007). Grounded theory researchers enter the field with initial questions, return to begin analysis and then return to the field to collect additional information to form their theory (Creswell, 2007). I did the same. The interviews were transcribed within three days after the interview took place. Journal entries were transcribed within three days after receiving them from the participants. The participants had a week to return their journal entries. As suggested by Creswell (2007), the researcher read transcripts multiple times, noting thoughts and reflections. These notes were used to create an open coding system. NVivo qualitative analysis software was utilized (QSR International, 2010).

Coding procedures adopted from Charmaz (2006) were utilized. This researcher utilized another coder, a Walden student during the coding process to ensure that inter-rater reliability was obtained (see Appendix H, Appendix I). Interrater reliability increases the likelihood that there will be agreement among the coders (Creswell, 2007). Incident-by-incident coding allows for comparison of similar experiences of the participants. As ideas begin to be created comparison of incidents previously coded can be utilized and properties of the emerging concept begin to formulate (Charmaz, 2006). Focused coding allows for earlier themes to emerge from the incident-to-incident data (Glaser, 1978). This type of coding is essential in identifying which codes make the most analytic sense when coding the data (Charmaz, 2006).

Axial coding as suggested by Stauss and Corbin (1990) was used to relate categories to subcategories and realign the data obtained in the initial coding process to the emerging analysis. The final coding procedure, theoretical coding identifies the primary categories in the focused coding and was utilized to relate the information obtained back to the research questions. The theoretical codes conceptualize how the substantive codes are related and help create a conceptual framework that then generates a theory (Charmaz, 2006).

Social constructive principles guided the analysis of this study. These principles suggest that researchers are part of the world they study and the data they collect. Additionally, these principles are guided by the fact that there are multiple realties and multiple experiences (Charmaz, 2006). Charmaz suggested "that any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it" (p.10).

I employed several techniques to ensure that this study is authentic, reliable and valid. To ensure validity I spent ample amount of time in the field collecting data, building rapport with the participants in order to establish trust in the relationship, obtaining word for word accounts in the interview process, taking extensive memos, and using inter-rater reliability procedures (Schensul & LeCompte, 1999). Reliability in qualitative research typically refers to the stability of multiple coders of the data sets or intercoder agreement (Creswell, 2007). Other methods used to ensure reliability were to document thorough memos and verbatim transcription of the interviews including pauses (Creswell).

The methods proposed by Lincoln and Guba (1985) that were also utilized to verify trustworthiness include: triangulation of data, incorporating the interview data from the participants, using the observation data, journaling excerpts and the researcher's memos to develop the themes present in the data. In grounded theory research, the researcher is the primary instrument, and as such, self-monitoring throughout the research process is a necessary component (Schensul & LeCompte, 1999). Self-reflection of the researcher satisfies this requirement. Utilizing thick description by which the researcher writes narratives that present details, emotions, actions, and meanings of interactions with other family members and hospital personnel experienced by the participants (Charmaz, 2006) in addition to quoting the participants adds to the trustworthiness of the study. I utilized an audit trail by keeping a record of all the interviews and keeping all tapes and field notes related to observations and the researcher's reflections in a safe storage place. An audit trail provides documentation of procedures and allows for determination of the dependability and confirmability of the findings. Member checking (see Appendix J) and taking the information back to the participants to ensure that their experience has been adequately documented will increase validity of the study.

Data Interpretation

Utilizing a grounded theory method, data interpretation used an analytical process taking into account inductive and deductive reasoning (Charmaz, 2006). In keeping with the grounded theory tradition of experts in the field the researcher although aware of previous theories and concepts related to this field will choose to refrain from developing preconceived theoretical interpretations. However, previous theories may be used later in the analysis to offer alternative explanations to the developed theory (Corbin & Strauss, 2008). Purposive sampling aided in this process. As previously mentioned, purposive sampling allows for the researcher to identify people, events, or information that will help to develop the theoretical categories (Charmaz, 2006). As the interview process proceeded, new concepts were developed, allowing for additional questions as the interviews progressed, which allowed for a theory to develop (Charmaz, 2006).

The basis for the interpretation began with the primary research question: To what extent is pediatric palliative care meeting its objectives of family support through the provision of quality interaction forums among close relatives? Analysis and interpretation of the data focused on the core categories and themes that emerged from the data (Creswell, 2007). Interpretation of the data focused on the lived experiences of the participants (Moustakas, 1994). The themes presented were compared to previous theories and analyzed according to social constructivist principles (Charmaz, 2006).

Summary of Research Design

Effective qualitative research is dependent on the researcher. The role of the researcher in qualitative research is both interviewer and interpreter. As suggested by Charmaz (2005) this type of interaction between the researcher and the participants leads to theorizing. Charmaz (2005) stresses the importance of the researcher incorporating one's own perspectives into the interview process. Data collection and analysis need to be conducted systematically to ensure reliability and validity of the results (Creswell, 2007). Social constructivist principles of Charmaz (2005, 2006) will be utilized to code and analyze the data. In this chapter, the research methods used ensured a systematic collection of data and analysis, addressed any concerns of participants' protection, and reviewed strategies implemented to ensure trustworthiness of the results. Final interpretation of the data was based on the primary research question: To what extent is pediatric palliative care meeting its objectives of family support through the provision of quality interaction forums among close relatives?

Chapter 4: Results

Introduction

This research study was developed to increase understanding of how close relatives experience the pediatric palliative care process. In this grounded theory study nine close relatives provided responses to interview questions as well as responses to journal prompts. Additionally, seven mothers provided responses to a journal prompt in order to triangulate the data. This chapter details how the data was generated, recorded, coded and securely stored; the process by which participants were recruited; and the steps used to verify the data and identify themes. The data collection procedures adhered to the ethical and confidential measures outlined in chapter 3.

Data Collection and Storage

After participants had been recruited and agreed to participate (see chapter 3) I scheduled interview times and places with each participant. I told each participant that a consent form would be sent to review and sign. Each participant was asked to bring the signed consent form to the interview. At the time of the interview, I reviewed the consent from outlining the option for the participant to withdraw at anytime and the confidentiality procedures. A copy of the signed consent form was given to each participant. After reviewing the consent form, I asked each participant if there were any questions and then spent a few minutes building some rapport through discussion of items not related to the study. Once it was time for the interview to begin, I reminded participants that each interview would be digitally recorded, transcribed, and password protected on the researcher's private laptop. At the end of the interview I thanked the participant and informed them that I may be contacting them in the future to further clarify interview items and that they would also be receiving a member checking form in which they would need to review and send back to me (see Appendix I). Additionally, at the close of the interview, the participants were given a self-addressed stamped envelope and a journal to complete two journal entries and return to me within 7 days. I conducted reflective journaling and note taking during and immediately following the interview. Interviews were transcribed within 3 days of the date of the interview. Journal entries were typed into a word document within 3 days of receipt. All transcribed interviews, journal entries, and a flash drive used to back up files were stored in a locked file cabinet. After all information had been received, collected, and transcribed I began the coding process. Upon completion of coding procedures, the data was sent to the peer coder to ensure reliability. After peer coder returned information, I reviewed her coding and noted similarities between the coding procedures. At this point I continued to analyze the data through the identification of initial codes, axial codes and theoretical codes using Nvivo 9 software (QSR International, 2010) and the researcher's coding system.

Profiles of Participants

The participants of this study included nine close relatives from five different families. The study also included seven mother participants used to triangulate the data. It should be noted that only two male participants were part of this study due to the fact that they were the only males who were part of the snowball sample and agreed to participate (see Table 1).

Table 1.

Profiles of Participants

Participant	Age (yrs.)	Gender	Child's Diagnosis	Status
1	67	Grandmother	Leukemia	Deceased
2	43	Aunt	Ependemoblastoma	Deceased
3	54	Grandmother	Rhabdomysarcoma	Living
4	39	Uncle	Acute myleiod leukemia	Deceased
5	57	Grandfather	Rhabdomyosarcoma	Living
6	55	Grandmother	Rhabdomyosarcoma	Living
7	35	Aunt	Acute myleiod leukemia	Deceased
8	66	Grandmother	Leukemia	Living
9	45	Aunt	Leukemia	Living

Results of Coding

As outlined in chapter 3, semi-structured interviews and journal entries were used for this study (Pennebraker and Beall,1986; Strauss & Corbin, 1990). The interviews were used to identify the perspectives of the close relatives in relation to their experience of the pediatric palliative care process. The journal entries were used to add to the depth of their experience and provide additional data of their perspectives. Data analysis begins with what Charmaz (2006) describes as *initial coding.* This process begins with transcribed digital recordings and interview notes completed during the interview process. Journal entries were also used to identify initial codes. Memo writing that occurred after the interviews were used to record the researcher's initial impressions of the interview and to record salient themes emerging at that time. I used

NVivo 9 software (QSI International, 2010) as well as my own process to completely review, sort, and analyze the data for accuracy of findings. Triangulation of the data through the parents' journal entries were also used in the coding of the data. The initial data units were then reconstructed in to larger units through focused coding. Initial codes were reviewed with less useful codes being discarded and smaller categories combined into larger categories. Commonalities in larger categories were then subdivided and reduced through axial coding. This was followed by the theoretical coding process which allowed for the emergence of themes and concepts from the interview data (Stauss & Corbin, 1990) which helped to clarify the research questions:

1. To what extent is pediatric palliative care meeting its objectives of family support through the provision of quality interaction forums (one-to-one and /or group) among close relatives?
2. To what extent do close relatives in pediatric palliative care feel supported, understood, and valued through their involvement in pediatric palliative care?
3. To what extent is a close relative's experience of pediatric palliative care impacted through interactions with other family members and healthcare professionals?
4. To what extent is a close relative's experience of pediatric palliative care impacted by factors of hope, uncertainty, adaptation, stress, and coping?

Parents' Responses to Journal Entries

In order to triangulate the data, parents were asked to complete a journal response to the question, "What have you learned from being in the pediatric palliative care process?" Seven mothers chose to participate. These mothers shared similar responses as the close relatives. Their journal entries were filled with details of emotional struggles, celebrating moments, relying on others and their faith, and their overall experience of the journey. A mother of child with leukemia (Participant 8) stated:

> Being a care provider of a sick child is a full time job in itself, but unfortunately many cannot just make this their number one priority. A family has to learn how to balance other children, work, and life in general. Being a care provider can be challenging, overwhelming and one of the most rewarding jobs you can have. The care you provide will have a huge impact on the healing process. The caregiver and patient will form this bond like no other. The most difficult part for our family is the limited outside support. We have great friends who help out where they can, work has been very supportive to both my husband and I. What keeps us going is our faith and that we are learning something from this experience. The biggest our daughter. She is this young girl with a huge soul. I have to keep the faith so she will. She's the one that has it hard and has endured so much. Many adults could learn from her. She is truly amazing and an inspiration to all who meet her.

Another mother of son battling leukemia (Participant 9) stated:

> It was the hardest thing I had ever had to do. He was making his own decisions but it was still hard to hear questions like "Do you want to be revived if you stop breathing?" Do you want to sign a DNR in other words? There were many details about when to be revived or not, for instance if he couldn't recognize his family and he was brain dead then he didn't want to be revived. When we started hospice they agreed to check his blood counts two times and would "allow" two blood transfusions per our agreement. The whole reason was to not keep him alive, just to prolong the pain and suffering. The night before he went into the three day coma that ended his life he was very happy and gave me a big hug and said he loved me and good night before I went to bed. He ate pizza and stayed up with his brother watching movies and playing video games. He asked his brother if he wanted any of his things in his room. He stayed up until 6:00 am when his brother got tired and said, "Why don't we go to bed?" The next day he got up to go to the bathroom around 8:00am and went back to bed. When I checked on him at 9:00am he didn't wake up and his temp was 104. So my lesson to anyone about my experience is live everyday with your loved ones in palliative care to the fullest and forget about dishes and dirty houses and keep love and happiness flowing daily. Stop thinking about the sad day to come and enjoy each moment like it will be the last forever. Don't focus on the doom!

These parents wanted to share their stories just as the close relatives wanted to. They had a need to share their story. The journal responses that were received from these mothers were pages and pages of their individual stories and their journey. Here is one mother's response of a boy with leukemia involving how she relied on others, "Grandma and Grandpa T. quickly stepped in and took care of him so we could return to work. We will never be able to thank them enough for all they have done for our family." Another mother of the child with enpedomblastoma (Participant 2) shared her experience:

> We knew we had a lot of decisions to make and wanted only the best for our daughter. She had surgery and the tumor was successfully removed. We were then crushed to find out she had cancer and we started doing tons of research to find out the best chance of a cure. You do not have a lot of time we were told the sooner we could get a treatment going it would be better for her. We contacted the hospital in Memphis. My husband talked to a radiation doctor this was on a Thursday and by Sunday we were there. We had to pack up our things and move some 400 miles away. We live in a small town so news travels fast. We were so overwhelmed with all the love and support from friends and family. Everyone pitched in and helped do whatever needed to be done while we were gone. You have enough worries when you are faced with such devastating news to know all your everyday things are being taken care of, relieves a lot of pressure. You are able to focus on your child. We will always be grateful for our family and friends who helped us out along the way. It would have been a lot harder without them. It breaks my heart to see people go through such a tragic ordeal without any support. I couldn't imagine it. We can only hope that someday no one has to go through it at all.

These parents also recognized that their journey is filled with memories and moments that live in their memories forever. A point where they relied on the doctors and also recognized the part of the journey that was no longer in their control. This mother of a son with leukemia (Participant 8 and 9) shared this:

> The tumor was very rare and aggressive it had spread throughout the brain. We were told that they would help us out in any way possible and do whatever we wanted to do, but there would be no cure for her. We asked her what she wanted to do; she said she wanted to go home. We wanted to do everything we could for her. When you are faced with such devastating news and not knowing how much time you have left with your child you want to make every moment precious. She wanted to be home on the farm and spend time with her family and friends. On November 14 we headed home thinking that we still had months to be with her and do things. It was later that evening she had a seizure and never came out of it. We had to stop at a hospital in West Plains, MO with her as we didn't feel we could get her home. The staff at the hospital was so very accommodating and helped us out in anyway. My husband and I laid on each side of her for several hours just watching her fight. It was the hardest thing we will ever go through. Her daddy picked her up and held her and she took her last breath in his arms. We feel through all of this journey everything that could have been done was done for her.

Another mother of a boy who has leukemia (Participant 8 and 9) had this to say:

> As we come to the end of treatment. I‘m starting to feel nervous and scared again. Not sure what the future has in store for our family. We have learned to take one day at a time and deal with it as it is handed to us. This has made me a stronger more visual and caring person. We have met a lot of great people including all the doctors and nurses. Plus other families that are going through the same thing. It is nice to have someone to talk to who understands how you are feeling at the time. Others that have no clue may say something that may upset you because they don’t understand, until they put on these shoes they will never know how quickly one’s life can be flipped upside down.

Remembering the child and embracing the moment was important to these mothers. One mother (Participant 1) had this to say, “My son is my hero and always will be. He has taught me so much in life than an adult has ever taught me. Although he lost his 3 year battle he is never forgotten in our community. We all love him and miss him dearly. We do what we can to keep his name alive.”

Initial Coding

The first step in the analysis process was to use open coding to identify, name and categorize close relatives experience of pediatric palliative care. An incident-to-incident approach was used to compare each incident with previous incidents in order to create a comparison of emerging themes (Charmaz, 2006). This type of coding proved beneficial because it allowed for comparison and clarification of each participant’s experience (see Table 2).

Table 2

Summary of Participant Responses

Question	Response	*n*
Q1: What thoughts and feelings did you have during this palliative care process?	Feeling uncertain	7
	Feeling helpless	5
	Feeling overwhelmed	3
	Feeling hopeful	4
	Wanting to be supportive	5
	Fear	3
	Feeling shocked	2
Q2: How would you describe your relationship with your grandchild, niece, or nephew?	Fun and loving	3
	Always joking around	3
	Part of me	1
	Very close	5
Q3: What people or places do you remember as being important?	Family	6
	Hospital staff	4
	Church	4
	Friends	3
Q4: What was the most difficult part of being in this process?	The unknown	3
	What they have to go through	5
	Seeing them suffer	5
	Feeling helpless	6
Q5: What important events do you remember?	Holidays	3
	Make A Wish trip	1
	Celebration of End of Chemo	1
	Coming home to see family	2
	Celebration of anniversary of death	1
	Celebration of birthdays	3
Q6: What persons do you remember as being important during this time?	Family	5
	God	6
	Friends	3
	Doctors	4
	Church	5
Q7: How did these persons help you to cope?	Helped my loved one	6
	Trust in God	6
	Faith	5

(table continues)

Journal Responses		
Q8: What have you learned from the pediatric care process?	Life-changing event	5
	Despair and sorrow	2
	Never the right words	4
	Seeing strength of child	4
	Optimism and hope	4
	Importance of family	5
	Cherish moments	5
	Dedication of staff	4
	Hard to see child suffer	5
	Heart wrenching	5
	Can see positives of experience	3
Q9: What do you think are the most important things I should know about your experience of pediatric palliative care?	Always have hope	4
	Family encourage to be there	1
	Family needs support	5
	Journey	5
	God is in control	4
	Feeling overwhelmed	5
	Cannot give up	4
	Cherish the moments	6

Charmaz (2006) suggested using gerunds to retain a sense of action and maintain focus on the fluidity of the participant's experience. In coding the journal response to: What have you learned from your experience? Through responses to this question a sense of the journey that these close relatives are on and how understanding their experience suggests that their experience is in some way similar to other persons involved in this experience, and in other ways unique to close relatives. Participant 7 said:

> The most heart-wrenching experience is hearing the word CANCER, not only for your grandbaby but what my son and daughter-in-law are faced with down the road of a life-time. The fear of loving their child and possibly losing him. The threat of death always at your door. The sadness of having to go through such an undertaking is so overwhelming. The Joy of having a new grandson with all the fingers, toes, etc. and knowing the joy and happiness he brings and the love we have shared with him, and afraid one day he will be taken from us. Watching our kids take this long journey all the trips to the hospitals, the sleepless night, hospital stays, giving medication an still being the loving and caring parents that has only grown for the better. With all the prayers,

> God's help and our children this has helped to be there whenever they needed to play, take care of whatever we have to do to share in this little angel's life. We love him so much.

Focused Coding

The second step in the analysis process was to synthesize and explain larger segments of data (Charmaz, 2006). Through this process less useful codes were eliminated and smaller categories were combined with larger categories or subdivided if responses were assigned the same code. At that point, repeated ideas surfaced which were then organized into larger themes that connected different codes and helped to identify the core category. The focused coding process constructed categories that could be readily analyzed in the subsequent axial coding phase. Descriptions of the focused coding results provide an elaboration of the constructs and emerging themes that facilitated the development of the grounded theory.

Helplessness

The participants related a variety of emotions that they experienced throughout this process. These emotions were relevant with responses to the question: "What thoughts and feelings did you have regarding your grandchild, niece, or nephew during this pediatric palliative care process? And this question: "What was the most difficult part?" It was evident from their long silences and flowing tears that responding to this question evoked various emotions that appeared to be just under the surface.

Participant 1said she was: "Just devastated. I just felt very sorry, very sad for my son and his wife. We had not experienced anything like this in our family. It broke my heart for them and for his siblings."

Participant 2 said:

> Just that it was very hard to see her go through all of this knowing there was nothing we could do for her. But be there for her. (Long pause). Um, she was a fighter. It was hard to know what to say to them. You wanted to ask what did you find out. And the nerve

> racking part of being back here and knowing she was having another MRI or another test. Waiting to find out what they found out. My stomach would be in turmoil, not knowing what am I going to say, or tell them if they call me and tell me that they found more or that it was back. Just waiting, that was hard. Hard to know especially towards the end. (Long pause.) I would say the unknown, but also because she was so little and having to go through something like this. It is sad that kids have to go through this . You always hear all the stories but you never think it will happen to you. We never thought in a million years it would happen. So I would say that is the hardest, seeing her be so young.

Participant 3 said:

> Just well when she was diagnosed just shock of all overwhelming just trying to process what she will go through, just trying to be there for support. Um, actually that first week I stayed up there with her and her mom I'm sorry I'm going to cry (cry and tears). I think mainly justI felt like my position was to be supportive as much as I could be for both of them (child and grandchild). I think seeing her suffer (crying) through treatment and she's been cancer free or whatever they call it for a year and a half. It seems like yesterday seeing her on the couch seeing her so sick and not being able to eat. It was like having my heart ripped out of my chest. I felt so helpless. It was almost like grieving for a lost loved one. It was really hard for my daughter to deal with it since she had to stay strong and positive for my granddaughter. That was just the hardest part seeing her so … I wish I could take a day of it for her. Helpless. I think just being helpless and taking the sickness away from her.

Participant 4 said:

> Well, obviously if he's gonna make it through the whole process. If he was going to be cured. In my experience of other relatives as they got near the end, they rebounded and got better. I think a lot of us thought he pretty much licked it and was going to overcome it. Then of course he took a turn for the worst and [silence].... and unfortunately he passed

Participant 5 said:

> My first thought was whether or not they would recover? [Long pause] at times I felt like there was a real good chance after it was diagnosed and they knew how to treat it. Um... it was better understood how they could get it her over it. In the beginning there was a lot of fear that they wouldn't be able to get a handle on it, because the type she had is a rare type. Not very many kids have that. And there hadn't been a lot of work done with that type of cancer. Rhadomyosarcoma. And it was just um... you know for the first week or 10 days there was just you know a lot of fear going back and forth of not knowing. The doctors weren't for sure what direction to go with it and until they developed a plan of what to use to combat it there was a lot of leaving us in limbo because they didn't know either. Once they formulated a plan things got a lot better. You felt like there was going to be success in the end.

Participant 7 said:

> Well, helplessness, thoughts of sorrow, thoughts of remorse, and an overwhelming sense of sheer utter helplessness." Just the feeling of not knowing and not being able too offer any assistance other than being there to support the family and friends and watching him cope with this disease and hope for a positive outcome. It was our daily, weekly routines to visit to see family and friends there. It wasn't an easy process, but having the genuine support for one another helped make the process a little easier to get through.

Hope

Participant 8 said:

> Uh.. my main thought is that it will be completely gone and he will have a normal life. [Long pause.] well... you know just pray everyday that he's gonna make it through this and you know that his dad and mom will have the strength and patience and the love uh...so that they can know make it through this and um... they will be closer together and have a good life.

Participant 9 said:

> It was a curse and a blessing. He doesn't know any better. It is hard to watch little ones go through this. But children can persevere. Hard to watch what they go through and all the pain. He would have to get a pic line put in and he would always say Oh, no "no owies". When he was a little dizzy after what they put in his pic line, he would say I'm a good boy. Right? You watched and crumble watching his mom having to do that with her child. I have great attachment to my nephew. But he's not my child so it helps being able to separate some of that connectivness to maybe help them. You look at them and the thing I will always take from them as much poisonas he had shoved into his body, he has made it and he is a loving little boy. As normal as I guess you can be.

Recognize the Childs Strength

Most of the participants were amazed and so utterly impressed with the strength of their grandchildren, nieces, and nephews as well as the parents of the child. They were taken back by the parents' ability to handle themselves so well and to be a source of strength for their child. This source of strength seemed to help the close relatives cope with what was occurring in their lives.

Participant 2 said:

> She was such a trooper and fighter through all of this. It's amazing to me how strong little kids are going through something so horrible. When my sister and her brother-in-law were told that their little girl had CANCER! I can't imagine how their hearts felt, cause it broke my heart tons and I was just her Aunt.

Participant 4 said: "He was so courageous for someone so young. As long as he had his parents around he had no fear. He had NO FEAR! He looked upon each day with unending joy and relentless courage."

Participant 6 said:

> Um…after gone a couple of days I went with her and she was they made a half cast from her chest up that covered her face and chest and I will never forget when she went in this is a new type of radiation that the machine spins around you. You lay on a bed and the machine spins around you to do the radiation. She was so proud that she wanted to show me that she could walk into that room, climb in the bed, put the mask on and they lock her down and she can't move. She crawled up there and I was just amazed, it didn't bother her at all. I was just like wow. She would take her headphones and put them in. Her favorite was um... cheetah girls. That's what she chose to listen to. Once they lock her down we all have to leave and she is in the room by herself while the radiation is going. It really set me back to see her have that done.

Participant 7 said:

> How we have a limited time not knowing when that day will come and watching my nephew not even given a chance to live and go through this and how strong he was at his young age and knowing that he was really support for us, watching how positive he was I just can't imagine as an adult going through this same process handling it as well as he did. In watching my nephew handle this experience with optimism and vigor made me further realize what a strong and amazing boy we had in our presence. I can only imagine what he and his family must of felt during this time. He taught me everything in his short time on Earth and to love unconditionally and let go of the "little things" that seem to get a hold of us and stay with us. Life is too short to worry about the little things.

Recognize Parent's Strength

Participant 3 said:

> My daughter was the other number one person. She was a rock and no matter what was going on with her child. She seemed so strong and I remember stayiung there with them. She would call me and ask if I could come Anna wants to watch a movie with grandma. I would go and watch a movie with her and that would be Emily's time that would be when

> she could let it all out and just cry. I just kept thinking I am so proud of her the strength and courage she showed and I think my granddaughter could see that in her mom and that she didn't give up. It could have been so easy for my daughter to fall apart but she didn't. She was a huge person in all of that.

Participant 8:

> [Crying] well I'm not sure that I would have been able to do that. And it's just I am in awe to watch my son be able to do all this stuff, I thought oh my God this is my baby (he's the youngest of 5) and how much he has grown and uh.. he has a whole different side to him. And um...and his wife thought when she was pregnant she was afraid she would not be a good mother. And uh...before he was diagnosed and I would go over there and stay for 3 nights a week and they would get up with him several times during the night and uh.... I watched her grow and she's like one of my kids. And uh..... I think she is a great mom and uh..[Crying].

Giving Support to Child and Parents

For these participants giving support became their way to give encouragement and respite to their families. Through giving support they were able to feel as if they were doing something to help eliminate some of the pain and suffering felt by their family members. Giving support also provided a sense of value to their experience.

Participant 2 said:

> My husband and I went down there alot. Spent the week when they first went down there. We always joked around, she called me Aunt Monkey. We were so fortunate that we got to spend that time with her. We could make it down there we were going to be down there. No matter what. It was too important to not be down there. Yes, very hard it was hard to always asking them if there was something you could do . You didn't know what to say. My husband went into the doctors appointments with them, because they were tyring to take everything in but he went in and wrote things down that the doctors were saying so they could go back and look later. It seemed to help them.

Participant 3 said:

> Just tyring to be there for support. Um, actually that first week I stayed up there with her and her mom. I'm sorry I'm going to cry [cry and tears].. I think mainly justI felt like my position was to be supportive as much as I could be for both of them [child and grandchild]. And that there was any part of it that I could be helpful or supportive I tried to be. Just seeing how hard it was with all those things together to get her where she was. Once my granddaughter was back home, my daughter would have to give her daily shots. I would show up at bedtime to help hold her down. It was very painful. I remember

> feeling so bad as soon as my granddaughter would see me she would know it was time for the shot. It was so great when they finally came up with one she could do at the clinic once a month.

Participant 4 said:

> Even though you’re there, sometimes the visits and what have you, there's not any thing you can do your just kind of a passenger and be there to play with him and talk to him. But really were just going through a waiting game, just like everyone else, just hoping for the best.

Participant 5 said:

> It was kind of a remote relationship. We were there all the time, but yet she didn't really respond to us because she was sick alot. She didn't feel good, she knew we were there, she knew we were there for her. At the same time she kind of wanted us at arm's distance from it. She didn't want us to be right on top of her helping her with stuff.

Participant 8 said:

> . We'd take him to get his blood work and I'd go to KC with them every 6 weeks to get the spinal tap and get the cancer treatment every 4 weeks. I have been there pretty much all the way. I am close to the situation. When he first started with the chemo and the steroids he was 22 months old, he wanted to eat all the time and every 5 minutes he wanted to eat. I'd pick him up and put him in the high chair and lay him back down. He got big and weak from not playing and running. We would lay down on the floor to play with him. He couldn't walk so we had a toy thing that he pushed around. I helped him with that and he learned how to walk again. [Crying…..] [Was it difficult to no what to say or do?] Not really too much. They have pretty much brought us in with them and you know I will ask questions and they will answer them and they have been real good about informing us of everything like how and why? We are getting older so alot of it is confusing. But, they have such an understanding of all of it it's just mind boggling.

Participant 9 said:

> Just physically being there, whatever support you could be and help out. We'd go out and visit and they could step out of the room. We became his playmates and they would go off in a different room. at first I was like that is kind of rude. When I started thinking about it it was the only time they had to breathe and to take a break. Visually, you were reminded of exactly of what you were dealing with. Some days were good some days not so good. You would go home and you feel so physically worn out and you say how could I be physically worn out when I am not even dealing with this everyday. You kind of pinch yourself into reality and then do what you can.

Celebrating and Making Memories

For these close relatives, making memories became increasingly important; each opportunity with the child to make a memorable moment was capitalized on. Close relatives spent many days with these children and their parents and each day brought with it an unforgettable moment. The responses to the question: What people or places do you remember as being important during this time? The responses expressed how these relatives felt about time spent with the child.

Participant 1 said:

> I would joke with him, he was just so sick, and I would ask if he wanted me to sing to him and he would just shake his head. I sang an old song to him, "When the red, red robin comes bop, bopping along." He would just giggle and that was good. The next time I would say do you want grandma to do the turkey gobble. He would shake his head no and he giggled. Everytime I would do it, he would giggle.

Participant 2 said:

> It was great, we had so much fun. We did makeovers in the hospital. We have tons of pictures of that. We were always joking around. Aumt Monkey came around because I was always joking with her trying to get her to laugh. She told me I was just like a monkey. And so she started calling me Aumt Monkey all the time. This is my Aunt monkey and my Uncle monkey. It was wonderful and I wouldn't have given anything up to be down there with her. Um the one that sticks out the most is when she finished chemo and we had the celebration of no more chemo. That was a big thing she was so excited and so excited to get to come home for awhile and just see family and friends she hadn't seen for a long time. My sister in law had just had a baby and Bailey could not wait to see him. Could not wait to get home and see him. She wanted so bad to get home and see him couldn't wait to get her hands on him and just be around all our family members that she hadn't gotten to see for along time.

Participant 3 said:

> Um, I think just the holidays were very huge. It seemed like every holiday she was in the hospital. I remember my daughter telling her I promise you won't be here at Chrsitmas. I was like Emily don't promise her. She was home at Christmas but she was there on New Years Eve. We celebrated New Years at the hospital. I think the holidays those events, just trying to keep it as fun as we could even though she wore her Halloweeen costome up there. On Halloween day she started running a fever and had to go the hospital in her

> cheeleading outfit for 2 days until I could get a bag up there. And then celebrations she got the Make a Wish trip. I was able to go with her and Emliy. She was able to take a friend and her mom.That was increadible just to be able to celebrate her and making it through that time. I had never been there and to experience that with her was incredible. Got to stay at Give Kids the World village.

Participant 4 said:

> Family, the things that we got to do with him during that time and then I would flashback to when we were younger. One of my favorite memories is a picture of me holding him at a bowling alley. He was quite a bit younger he wasn't sick at that time. It's just one of my favorite memories of him, he was always a curious little guy. (Long silence.) well even with such a serious thing like this illness again alot of the events focused around family and we celebrated his birthdays there. A few times we would have pizza parties with extended family we just tried to make it as painless as possible considering the circumstances. We celebrate the anniversary of his death and his birthday. Alot of the shared memories from other family members really kind of helps strengthen the bond that we have as a family. Kind of helps us knowing that we are all sharing in the loss and the grieving.

Participant 5 said:

> And this was not a bad situation, but we left there one night she had hair we came back the next day and she didn't have any. She thought it would be cool to have not hair because I told her when she lost hers I would shave my head. So that was kind of a shocker when I walked in and saw her with no hair. Yes, I did shave mine.

Participant 8 said:

> I don't know… there's been several times that he'd say that grandma you he bestest grandma. and just little things uh.. He turned 5 yesterday and for his birthday he called me up about 3 weeks before and he said grandma, “I seen at the Walmart in Ottawa had a Lightening Mcqueen Guitar.” He said, “ I'd like to have you get that for my birthday.” We looked around and found one a week before his birthday he said I'm getting a guitar for my birthday. He turned to me and said grandma I called you and told you I wanted that for my birthday. We have lots of pictures of us playing with him. He'd try to brush my teeth. He and grandpa built towers together. We played constantly on the floor. It's not easy to do, my husband siad he didn't know playing could be so hard. Celebrating the end of treatment. All the fun, laughter, and good times we had making biscuits, cookies, playing cars and trucks, make towers, swing etc. have well been worth all the time in the world. We don’t take life for granted. Take all of it everyday and love what we’ve had. My grandson always says, “Grandma you the Bestes.

Participant 9 said:

> Our favorite time is since he was little bitty I always called him my little "dawhly" "Your my dawhly." When he started talking he would talk in third person not so much anymore but I think he did it because he was associating with what he was thinking with what he was feeling. He'd say I am your dawhly, dawhly. I think probably I spent a lot of time with him a lot of time. I didn't have the leisure of sitting up in the hosptial with them but with the exception of this last year I was probably up there 2 or 3 times a week and in the beginning every night. I spent a lot of time with him. He knows who I am. Well, honestly spending time with him. This last year has been hardest with me because I have had personal issues so I haven't been able to be out there as much as I want to be. For me it was about being with him, just seeing him, touching him. That was proof to me that he was alive. If I really think about it. To physically see him, to hold him, to smell him, to see him laugh. and just let him come up and lay his head on my shoulder that was good. That meant he was still here and is still here and that was good enough for another day. When you don't see him, and then you hear things happening and you start to think what if and you start playing that game and you have to shut it down real quick.

Reliance on the Doctors, Healthcare Staff, and Others

All of the close relatives' had an appreciation for the healthcare staff and a reliance on them to take care of their grandchild, nephew or niece. Most of them had a very positive experience with the healthcare system and built relationships with these individuals. Additionally, these close relatives had to trust these people who were charged with taking care of their loved ones and ensuring that they did everything possible to find a cure.

Participant 1 said:

"Trying to keep us together. It was a very nice place for him and the people there are just wonderful. Not a cross person there. Hospice house very special place. I was glad there was a hospice house."

Participant 2 said:

> Seeing the doctors the nurses and everything. Being there in such a bad situation they made it seem like not a bad situation. How did they do that? It has to be hard on them? They made the whole hospital seem like a fun place for the kids to be. See these kids riding on their tricycles and in wagons. It is just amazing. These kids are so sick but thery are having a great time which I think is so important. Have some of that fun time. Her doctor was great. She had Empendymoblastoma right above the eye. Her doctor

> was very supportive and very nice didn't mind that my husband was coming in and asking quesitons that they wouldn't ask. They [the parents] were looking at stuff on the Internet and he was fine with that. He did not get angry that they were checking options. He and the nurses in that area and everywhere were so fun and supportive.

Participant 3 said:

> Um, well persons her doctors for sure. Her doctor from the beginning has just been a go-getter. She didn't candycoat anything. Everything was very upfront. She had a way of being sympathetic but we liked that she didn't sugar coat anything. We knew what to expect. I guess I appreciated that. I think we had alot to do with her seeing that there was more than what she knew from medicine. There was no reason she should have been alive when taken to the hospital because of her airway it was almost completely blocked.. My daughter had taken her to the doctor and the doctor said that she shouldn't be alive and my daughter said well God isn't done with her yet. That was a turning point in their reasoning and in her education made her step back and look at this that not everything we know comes from books, there is something greater; whether it is a higher being, support of the family or whatever. She said I had to look at that and know it just isn't me and what I can do and what medicine can do. That was big for a doctor to admit that. The other person I should tell you about is the child life coarches. That is what my granddaughter wants to be when she grows up. She has been so taken by them and there support. She loves them. Everytime she goes up there that is who she wants to see. That is what she wants to be. She wants to be a cancer doctor or life coach for cancer kids. I just think that made a huge impact on her. I remember when one of them brought her a brand new Barbie in a package and they were playing with her and combing her hair. Asked my granddaughter if she wanted to cut her hair. You can cut her [Barbie's] hair if you want. She did a great job on it. That was incredible. We would not have let her cut her Barbie's hair for nothing. This was her way of letting my granddaughter be creative. We still have that Barbie. It was just really fun and the way they helped her through different procedures they were incredible. I have gained a greater respect for the people serving in the medical field. The professionalism I witnessed, along with the great compassion and care given to my granddaughter, has been truly inspirational. Without, each one's talents and expertise, her diagnosis, treatment, and recovery would not have been achieved with such great success.

Participant 4 said:

> The family is encouraged to spend as much time as the care facility allows with the loved one and at times to help with the care when the nurses are busy. The medical personnel sees to your loved ones every need and sees that the doctors' orders are followed. The staff is very helpful in answering any questions you might have or will get the answers for you. There are counselor's advisors available to help with the financial side of the process. They will keep in touch with the insurance company on your behalf so you aren't stressed about that as well. The emergency response team is always ready to step in when the need arises which gives the families peace of mind. That the doctors and medical personnel are very compassionate informative and will go above and beyond

> at times to see that your loved one gets the best care they need. They are supportive of the families and encourage spending as much time as allowed with the loved on. I also feel it is important that there are counselors/support groups available to help with the financial side of the care and support for the coping of being ill or having a loved one with an illness.

Participant 5 said:

> Well, once we got to know the oncologist, I thought that was really important because you kind of to build a trust with the doctor and she was really on top of everything that she did she was well versed and rounded in what her treatment plan was going to be. She had consulted some of the best doctors that were familiar with this type of cancer. One of them that was foremost in the treatment in this cancer was [one of our doctor's best friends]. Once we learned that and we got to visit with her. You kind of start building a trust with her once you build that you can feel a light at the end of the tunnel. Well like I said earlier the doctor as one um being able to have trust in what she was telling you, what she was going to do. The time, the energy, the care and the compassion that's given to each child that we saw the doctor and staff deal to each one of them.

Participant 6 said:

> This is a vital element in the healthcare environment. The staff is extremely dedicated to the patient and their families. Their career in this field is a true calling. While they are accustomed to seeing patients at the most dire time of their life; they treat each patient as an individual with needs that are dependent on their immediate and constant attention. The patient is in their hands and is reliant upon their medical expertise to help them through this process. I commend those who chose this calling as they are truly "God's helpers.

Participant 7 said:

> I was greatly impressed/gratified by the nursing staff/caretakers that looked after my nephew. The prospect of a terminal illness is a scary enough thing to encounter, but for it to happen to a child is heartbreaking. A dying child is a sad and gut-wrenching experience, but without the professional caregivers and family that he was surrounded by, it would have been impossible to cope.

Participant 8 said: "We have been so close with the kids and the doctors and interacting with everything, we have had alot of support with all the doctors and nurses and each other."

Participant 9 said:

> When they first started, the hospital gave them tons of information about the trial they were in. I think resource wise was great. Not only did they talk about it, they laid out everything. This is what to expect if this and this happens, you pick up the phone. They

> had a nurse 24/7. I never ever saw it that the nurse was not available to them. They alwasy responded in a timely manner. I will sing the praises to them forever. Because they did such a great job. Um....the one thing if you had a perfect world. What a great thing it would be if everyone 's schedules would allow the families to sit down with a whole med team and talk about this is what is going on this week. Some sort of once a week or once a month to sit down with your team and say this is what is going on, we called you this many times, can you help us alleviate this or this. Maybe that would be beneficial. Probably would never work. But maybe with Facebook it would work.

Reliance on God

These close relatives were highly reliant on their faith and their belief in God to get them through this process. They put that which they could not control in his hands and relied on their faith to somehow pull them through. Reliance on God meant that they could surrender control to a higher power. Their responses to: “What helped you cope?” gave credence to their trust in God, and their reliance on their faith to deal with the darkest of days.

Participant 1 said: “Only God knows why and our church. I knew he was going to be gone into the arm's of Jesus. But that comforted us. Because babies are special to God I think. Only God knows why.”

Participant 3 said:

> Our church family um, are pastor and honestly God. I mean I feel like all of our hope is in Him. I kept thinking I wouldn't even go on the Internet to read things about it. Because I couldn't go there. I was just going to take it as it comes. Just hope in God and just knowing He sees the big picture. We don't necessarily know what is going to happen tomorrow but He already has the plan in store for us and He will get us through it a day at a time. The thing that helped me get through all of this... people who don't have the Lord in situations like this what do you do? God took us through this. One of the first few days that I was at the hospital, I leaned over to my granddaughter I told her we don't expect you to understand but one thing you can count on is God will be with you the whole way. We don't know what His answer is going to be but just remember that.

Participant 5 said: “[Long silence]....well you know [uh] having put faith in God and knowing that He will pull you through... knowing that he is not bringing anything he knows you won't be able to handle.. having faith in God.”

Participant 7 said:

> We all had hope and knew he was a strong-willed little guy. There for a time, he did improve and I thought for certain he'd beaten it. I mean this was my nephew! Surely God wouldn't take this sweet, innocent, loving little boy from us right? After all, of there are those in the world out to harm others who live to be 90, how would He let my nephew die, right? Right?

Participant 8 said:

> I just pray everyday that he's gonna make it through this and you know that his dad and mom will have the strength and patience and the love uh...so that they can you know make it through this and um... they will be closer together and have a good life. I would say our priest has been a big support. With all the prayers, God's help and our children this has helped to be there whenever they needed to play, take care of whatever we have to do to share in this little angel's life. We love him so much. That God is everywhere and He sure has been here for all of us. We have learned to have more patience and that our pain is nothing as to what our grandson has had to go through and his parents.

Participant 9 stated:

> Well during the pain I have a very strong personal faith and the times I would cringe at some of the things I would see my coping was praying for him. I believe it is in someone else's hand. I don't know anybody that honestly could see someone suffer especially a child and not think to yourself God why can't it be me. On some level yeah. I would have traded places with him in a heartbeat if it would have change anything. I knew to pray to God that He would supercede and make it not be there in his body. My faith, I cannot ever discount that. Seek the guidance and peace that I personally know only comes away from God…in the times when words, my presence, my help, my "whatever" was not enough… my prayers were, it is when I would lay my nephew and his illness at God's feet—that I truly found peace—it was when I could lift my brother and his wife to God in prayers that I found peace----There are many times –when I don't question at all…God sending angels to lift his weary little body –to a place of rest so that he could make it through another day.

Axial Coding

The third phase of analysis, axial coding, followed a social constructivist approach developed by Charmaz (2006). This involved identifying the categories in the focused coding for the linkages among them. This approach is less formal than the one advocated by Strauss and Corbin (1990). Through axial coding; relationships between the categories are defined.

Statements in the interviews and journal entries which indicated how the participants have experienced palliative care were underlined and highlighted. Charmaz (2006) contends that axial coding "helps to clarify and to extend the analytic power of your emerging ideas" (p. 63). In this process, the themes of *finding meaning, engaging in dual-care giving, and embracing the moment* highlighted the perspectives of close relatives in the pediatric palliative care process.

Finding Meaning: In the beginning of the process, close relatives find themselves struggling to find answers. They question how and why this could happen to a child? They are filled with feelings of helplessness, shock, sadness, and devastation. They question how could this happen to our loved one? How could this happen to a child? They entertain their uncertainties and their fears. They look for answers in the doctors, the nurses, the lab techs, whoever can help them. They struggle between dealing with the pain and suffering and never losing hope. They struggle to understand why their grandchild would be so willing to climb up on the radiation table and take her treatment. They struggle when they remember their niece's face when she lost her hair and had to wear a wig. But as the process continues they begin to recognize that there is meaning in this situation. They create meaning because that is one way they can control the situation:

Participant 9 stated:

> In watching my nephew handle this experience with optimism and vigor made me further realize what a strong and amazing boy we had in our presence. I can only imagine what he and his family must have felt during this time. He taught me everything in his short time on Earth and to love unconditionally and let go of the "little things" that seem to get a hold of us and stay with us. Life is too short to worry about the little thing. The importance should be on your family and loved ones. It is important to cherish every moment and never leave a loved one without a proper goodbye as you never know if it will be the last time you see them.

Another close relative (participant 9) wrote this poem as a way to find meaning in this journey:

The Storm

You came home today, all snuggled and warm
Eyes so beautiful, perfect in every way….
Behind those eyes, something was stirring
None of us knew what storm was brewing….
Moments turned to days, days to weeks
All seemed normal, you grew bigger and began to speak….
But something was brewing, none of us knew
The storm that was coming, its mission to destroy…
Oh how beautiful to hold you so close
To hear you breathe, to tickle your nose
Your eyes started showing, something not right
You were getting sick more often staying up late at night
The weather was changing a cold front came in
The beginning of the storm, the relentless as it began….
To the doctor you went, many times not sure
The doctors couldn't see the beginning of this storm…
A cold, a virus, the flu they would say
But behind your eyes the diagnosis was at bay
We all will remember the startling news
Our precious …….bug did not have the flu
They called it ALL the diagnosis confirmed
You body had been taken by a tremendous deadly storm
Cells colliding, your immune system not strong
The storm unleashed, its hellish power….
Your little weak body, your parent so scared
The treatments continued for hours upon hours….
Your bright eyes faded, though a smile shown through
The weeks, the months of this unending gloom
How do you comfort a deathly ill child
How do you explain, the fear deep inside
We held on so tightly to each passing day
Praying that God would please stop the rain
Prayers often answered, when sunshine appeared
The storm was passing, though its presence still near….
More time passed, your little boy held strong
The treatments are working a clearing in the fog…..
It is safe to believe that the storm has passed
Is it okay to smile and rejoice at last….
Can we hold on to promises, can we put this in the past
Somebody tell us is it over at last…..
We look into your eyes and now truly see
A smile, a glimmer of the boy meant to be….
To be without bruises, to be without pain
No more owies, your eyes shown once again….

To live each day, with purpose and joy
You are , A Blessing, Our Joy

Engaging in Dual Care giving

Close relatives find themselves engaging in dual care giving role during their journey. They are not only there to care for their niece, nephew, or grandchild, but they are also there to care for the child's parents. They find themselves being there to play with the child so the parents can take a break; they want to be there for the parents so they can be supportive as much as they can. From being there to help with medical procedures or being there for someone to cry too or lean on; these close relatives are there. Participant 9 stated:

> I encourage anyone who ever has this personally affect them---Become involved….help where you can …be the resting place for parents….allow them brief moments of escape from the daily reminder of the illness. Don't be afraid to cry, to be afraid to talk through the fears that no one escapes—sometimes just listening can provide moments of peace to the parent.

Participant 3 stated: "I think mainly just I felt like my position was to be supportive as much as I could be for both of them (child and grandchild)." *Engaging in a dual-care giving role* means putting your family members' needs before your own. Participant 3 stated: "I remember she would call me in the middle of the night and ask if I could come because she wants to watch a movie with grandma. I would go and watch a movie with her and that would be Emily's time that would be when she could let it all out and just cry." It means hiding your feelings in order to be strong for your loved ones. *Engaging in dual-care giving* means at times stepping in and caretaking while the child's parents take a much needed rest, as one close relative (participant 9) stated:

> I can't imagine how their hearts felt, cause it broke my heart tons and I was just her Aunt. Our family has always been very close and we gave them all the support we could! Which I feel is very important to help them through such a horrible process. One of the most important things is the support they need while going through this process! All of our family was very supportive through the whole time and I believe that is what helped.

Being a caregiver you also feel like that child is a part of you, that you see yourself in them and you don't want them to suffer. You want them to be pain free and you want to be the one to take on their burden. One close relative stated: "It is like taking your heart and ripping it out to know what they might possibly have ahead of them. I think we are extremely close, she is kind of like me, I feel she is a part of me." These close relatives recognized that they don't want any family member to suffer or to be in pain, and so thus the desire to take it all away and to take their place persists.

Embracing the Moment

Embracing the moment means living in the present. Seeing each moment as a gift and recognizing that each moment may be the last. Embracing the moment means that there will be negative moments and positive ones but that each of them creates meaning; looking at each word, each action, each feeling as individually memorable makes embracing the moment so meaningful. Participant 9 stated:

> Mostly <u>Embrace---</u>Embrace every moment that you can spare to spend time with the child or individual who is afflicted—Spend each moment as though it were the last---make the moments count in real tangible ways-laugh—cry---play—hold—hug---embrace---read a book---sing a song---Just engage the individual help them to LIVE by walking beside….and last but not least ….seek the guidance and peace that I personally know only comes away from God…in the times when words, my presence, my help, my "whatever" was not enough… my Prayers were, it is when I would lay my nephew and his illness at God's feet—that I truly found peace—it was when I could lift my brother and his wife to God in prayers that I found peace----There are many times –when I don't question at all…God sending angels to lift his weary little body –to a place of rest so that he could make it through another day.

Embracing the moment; meant connecting with the loved one in an individualistic way so that the relationship is special on its own merit. All participants wanted to engage in special moments with their niece, nephew, or grandchild. These moments sometimes brought them to tears and sometimes joy, but they all cherished each moment they spent with their loved one.

Throughout their journey, these close relatives embraced the moment because it is another part of the journey they had control over. Participant 9 stated:

> Never Give Up….Have faith….Create moments to celebrate each day as though it was the last—None of us know our time on this earth—and when dealing with a small child—it is too easy to be overcome by the magnitude of Sorrow-Pain—Anger to witness what this disease does to them—But I believe if we try hard enough that even in the midst of such grief and pain—we truly can find peace and happiness. He is my "Dawliee" and I am one Blessed Aunt of many who have and are loved by this remarkable Little boy.

These close relatives learned to take every moment that was given to them and make the best of it—embrace it even if it meant under less desirable circumstances. Looking at the special memories of a make a wish trip or being called "Aunt monkey" and then years later finding a necklace to symbolize that connection. As participant 3 said:

> I think just the holidays were very huge. It seemed like every holiday she was in the hospital. I remember my daughter telling her I promise you won't be here at Chrsitmasn I was like don't promise her. She was here at Christmas bu tshe was there on New Years Eve. We celebrated New Years at the hospital. I think the holidays and those events, just trying to keep it as fun as we could even though she wore her Halloweeen costome up there. On Hallwoeen day, she started running a fever and had to go the hospitl in her cheeleading outfit for 2 days until I could get a bag up there.

The journals that the close relatives responded to have many pictures of special moments along their journey. They embraced these moments, these chances to connect with their loved one, and for these close relatives; these moments will never be forgotten. For the close relatives who have lost their loved one and those who still live in fear that their loved one may someday relapse; these memories keep the child's spirit alive and make the journey more bearable. Participant 8 stated:

> All the fun, laughter, and good times we had making biscuits, cookies, playing cars and trucks, make towers, swing etc has well been worth all the time in the world. We don't take life for granted. Take all of it every day and love what we've had. My grandson always says, Grandma you the Bestes.

Participant 4 stated:

> Even now, many years later, he is still influencing others in a positive way—those that have never met him are inspired by his story, just as I'm inspired to be in the healthcare field. If I can help save a young guy sick with a cancer or even prevent it at all, then maybe it will allow a little of my nephew to live on through that child.

Theoretical Coding

The final coding procedure used in this analysis was theoretical coding which identifies the primary categories in the focused coding and are utilized to relate the information obtained back to the research questions. The primary research question in this study was: To what extent is pediatric palliative care meeting its objectives of family support through the provision of quality interaction forums (one-to-one and/or group) among close relatives? The secondary research questions in this study were: 1) To what extent do close relatives in pediatric palliative care feel supported, understood and valued through their involvement in pediatric palliative care? 2) To what extent is a close relative's experience of pediatric palliative care impacted through interactions with other family members and healthcare professionals? and 3) To what extent is a close relative's experience of pediatric palliative care impacted by factors of hope, uncertainty, adaptation, stress, and coping? The theoretical codes conceptualize how the substantive codes are related and help create a conceptual framework that then generates a theory (Charmaz, 2006). After utilizing the coding procedures of identifying initial codes and themes and then subdividing these themes into larger categories through focused coding a theory began to emerge. At this point, axial coding procedures identified and connected the relationships between the themes. Finally, theoretical coding procedures were used in which the themes obtained through focused coding were related back to the primary research questions. Based on the findings of this study through the coding procedures utilized by the researcher there is an overriding theory of s*urrendering to the journey,* through which close relatives experience pediatric palliative care. This overriding theory of *Surrendering to the Journey* encompasses three main themes of *finding meaning, engaging in dual care giving, and embracing the moment. surrendering to the journey* is all encompassing of the three main themes. For these close relatives s*urrendering to the journey* meant letting go of what they had no control over while holding on to that which they had control: *finding meaning, engaging in dual care giving, and embracing the moment.* Figure 1 represents the process to formulate the model of this theory from the coding procedures.

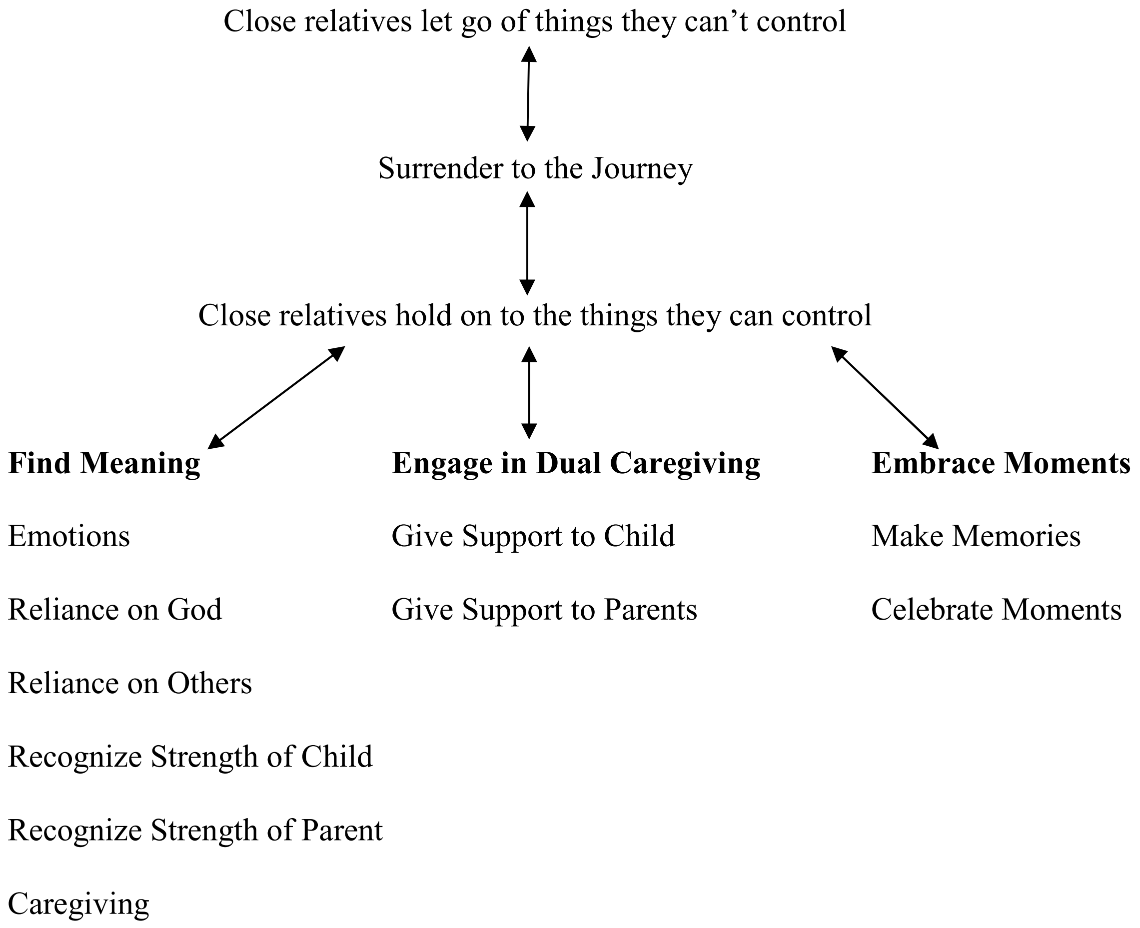

Figure 1. Close Relatives Process

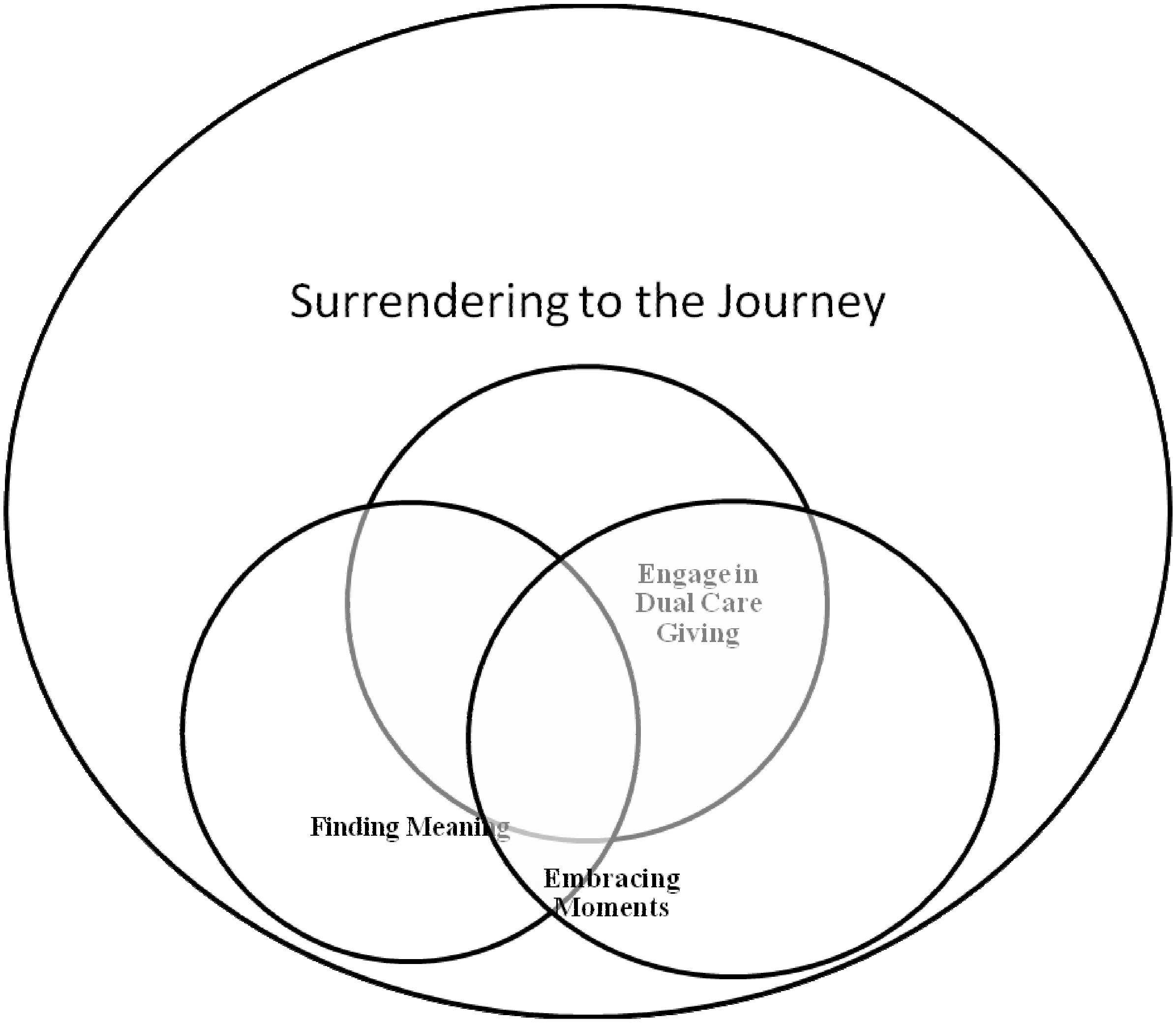

Figure 2. Surrendering to the Journey

As one loving grandmother (Participant 3) so eloquently wrote about her journey:

> I'd like to paint a mental picture if I may…
> Her Life Song…in the hands of the great "Maestro"
> Picture her caregivers as an orchestra. Each member with his or her own unique talents, wisdom, style…just waiting for the opportunity for their specific instrument to be used by the great "Maestro" (our God). God, the Creator and Author of life, knowing the ultimate song that her life would represent orchestrated in precise timing each instrument's involvement based on the individual's gifts He had given them. Those instruments were her mom, cancer doctor, ENT surgeon, radiology doctor, endocrinologist, nurses, lab technicians, child life coaches, pharmacists, medicines, hospitals, ER's, Care pages, and others too numerous to mention separately. All were used in his perfect timing. The music created was her life song. We the audience, (grandparents, great-grandparents,

> aunts and uncles, cousins, extended family, friends, co-workers, fellow students, and even those who never personally knew her) are blessed to be witnesses of her incredible masterpiece. At times, her song brought us to tears for the pain and suffering she endured and to great joy for her amazing strides of recovery. But mostly, it gave us an incredible sense of her strength, and her desire to be used by her "Maestro" Throughout her journey we could always see God's hand conducting. Only He knows how long her song will be, but I know it will be sung through all eternity.

Participant 8 had this to say about her journey:

> No one should ever have to witness or go through this type of journey, it a times is the most scary, stressful, doubtful, exhausting experience to have and that comes from my perspective only as his Aunt. His parents endured this and much more every minute—every hour—everyday—and managed to take care of a very ill child and still try to have some "normal" aspect to their daily lives. I encourage anyone who ever has this personally affect them---Become involved….help where you can …be the resting place for parents….allow them brief moments of escape from the daily reminder of the illness. Don't be afraid to cry, to be afraid to talk through the fears that no one escapes—sometimes just listening can provide moments of peace to the parent—Mostly Embrace---Embrace every moment that you can spare to spend time with the child or individual who is afflicted—Spend each moment as though it were the last---make the moments count in real tangible ways-laugh—cry---play—hold—hug---embrace---read a book---sing a song---Just engage the individual help them to LIVE by walking beside….and last but not least ….seek the guidance and peace that I personally know only comes away from God…in the times when words, my presence, my help, my "whatever" was not enough… my Prayers were, it is when I would lay my nephew and his illness at God's feet—that I truly found peace—it was when I could lift my brother and his wife to God in prayers that I found peace----There are many times –when I don't question at all…God sending angels to lift his weary little body –to a place of rest so that he could make it through another day…And so the journey comes to a milestone, my 5 year old nephew has survived the Biggest hurdle—of countless treatments—countless tests—countless days of Pain- and physical torture from his little feet to the tip of his head. To put to rest ????? No there is great joy in the next part of his recovery—but the unknown brings—much anxiety and fear of the unknown…. So- Live-Laugh-Love….Have faith..pray often—Be thankful for each day that dawns and you see him smiling back….To know my nephew is to Love him and Be Loved. This I know and am so grateful.

Treatment of Discrepant Cases

In keeping with the constructivist approach to grounded theory, responses that were discrepant or disconfirming were folded in the results (Charmaz, 2006). Data from the interviews and journal responses represented how participants understood their experience of palliative care. The data was analyzed for shared commonalities of the coding process, recognizing that individual differences accounted for individual differences and how each experience was constructed or reconstructed by the participants. In this analysis, discrepant and disconfirming cases were folded into the analysis as examples that differed or expanded the content or themes of the coding process.

Evidence of Quality

Ensuring quality of evidence is more complicated in qualitative research. Charmaz (2006) suggested that verification of trustworthiness of constructed grounded theory research requires careful attention to the role of the researcher. Utilizing memo writing and a reflection journal served as a means of self-monitoring. These tools allowed me to consider aspects of data collection and analysis including: reactions to participants' responses, interview techniques, and the linkages between participants and their experiences and how these related to the analysis.

Evidence of quality can also be inferred by the transparency of the analysis (Auerbach & Silverstein, 2003). This chapter provided details of memo-writing, journal reflections, and coding procedures so that other reviewers can clearly examine the steps used in reporting the findings and conducting the analysis. Member checking and taking the information back to the participants to ensure that their experience has been adequately documented increased the validity of the study. I utilized an audit trail by keeping a record of all the interviews and keeping all tapes and field notes related to observations and my reflections in a safe storage place. An audit trail provides documentation of procedures and allows for determination of the dependability and confirmability of the findings. Utilizing thick description by which the researcher writes narratives that present details, emotions, actions, and meanings of interactions with other family members and hospital personnel experienced by the participants (Charmaz, 2006) in addition to quoting the participants adds to the trustworthiness of the study.

Finally, using another Walden student to code the data increases the reliability of the study. Reliability in qualitative research typically refers to the stability of multiple coders of the data sets or intercoder agreement (Creswell, 2007). Triangulation of the data in qualitative research is another method used to increase quality of evidence. The parents' journal responses were coded to identify similar themes present in the close relatives' data sets.

Summary and Analysis of Results

This chapter provided a detailed report of data collection procedures and data analysis. Procedures related to interviewing participants, transcribing data, and peer coder duties were outlined. The interviews of the close relatives presented data of perspectives of their experience including their feelings, their roles, and their attempts to make sense of their experiences. Tables were presented indicating initial coding procedures, that included an incident-to-incident process suggested by (Charmaz, 2006), followed by a focus coding process that identified major themes present in the data including feelings of hope and helplessness, reliance on God, healthcare staff and others, celebrating and making memories, giving support, and recognizing strength of loved ones. Axial coding was used to identify properties among categories. The final selective coding process identified the central themes that emerged from the coding processes and were reformulated as factors that influenced the central concept. A figure (Figure 2) of the grounded theory that emerged was presented. The core theoretical concept that emerged was s*urrendering to the journey.* This concept encompasses three other factors that create the theory: *finding meaning, engaging in dual-care giving, and embracing the moment*. The chapter concluded with how evidence of quality was demonstrated. Chapter 5 will provide interpretation and analysis that emerged from the results, social change impact, and directions for future research.

Chapter 5: Discussion

Introduction

Pediatric palliative care became a priority in the health care field when the Initiative for Pediatric Palliative Care was established in 1998 as an education research forum for pediatric palliative care (AAP, 1998). The focus of research in this area has generally included the experience of parents, the child, the siblings, and the healthcare system. However, no research has been conducted to identify the experience of the close relatives. The Initiative for Pediatric Palliative Care (AAP, 1998) American Academy of Pediatrics (AAP, 2000) Institute of Medicine (IOM, 2002) and the World Health Organization (WHO, 2009) stressed the importance of pediatric care involving the child and the family, including close relatives. Although these organizations have agreed that this is a priority for high quality pediatric palliative care, no research with relatives in pediatric palliative care currently exists. A qualitative grounded theory methodology was used to understand how close relatives experience pediatric palliative care and how their experience can be used to fill a gap in the healthcare arena with regards to palliative care programming. Implications from the findings of this study will be described and a rationale for how the conceptual framework that resulted in this study can be used in other areas will be presented. The intent of this study was to substantiate a theory that explained how close relatives experience pediatric palliative care and in what ways their experience can be valued in the healthcare system.

Volunteers for this study were solicited partially through an agency located in the Midwest that serves people in need of palliative and hospice services. This avenue did not bring enough volunteers, so the researcher went back to the IRB to obtain permission to utilize a snowball sample in which members are recruited essentially through word of mouth. This recruiting method proved beneficial and nine close relatives readily volunteered to participate. Additionally, seven mothers of the children secured through a snowball sample and were used to triangulate the data. Research questions focused on how these close relatives experience palliative care including: their thoughts and feelings, their interactions with family members, their value or part in the process, and whether or not their needs are being met. Journaling responses from mothers of children in pediatric palliative care were used as a means of triangulating the data and increasing quality of evidence in this study.

Interpretation of Findings

Surrendering to the Journey

In addressing the research questions as the experience of the close relatives and how their needs are being met through the healthcare system it was apparent that these close relatives see their experience as a journey that is out of their control, one that they must surrender too. Their journey is filled with psychological, physical, emotional, and spiritual symptoms that often are overlooked. This is similar to the findings of Theunissen, Hoogerbrugge, Achterberg, Vernooij-Dassen, and van den Ende (2006), who found that children and parents often exhibit many psychological and physical symptoms that are readily missed. This is apparently no different for close relatives. It was important for this researcher to gain a better understanding of the close relatives through a qualitative analysis. Meert, Briller, Schim, Thruston, and Kabel (2009) uncovered similar findings when they examined parents' needs while in the pediatric palliative care process. The finding of this study revealed that throughout their journey close relatives' struggle with positive and negative feelings, recognize the strength of their loved ones, engage in caregiving, create memories, and live in the moment. For these close relatives who feared losing or who had lost their loved one ensuring that the child was not forgotten was of upmost importance. This was similar to the findings of Woodgate and Degner (2005) who utilized a grounded theory to substantiate how families perceived the cancer process. Their findings showed that the families were focused on keeping the child's spirit alive.

Results of this study show that close relatives are highly impacted by their experience and that they struggle with many of the same experiences as parents, children, and siblings. Beckett (2000) suggested that when one member of the family is impacted by a stressor all family members are impacted; and the results of this study suggest that this includes close relatives. Patterson et al. (2004) also found that the diagnosis of the child impacts the entire family system. Close relatives are part of this system and they also experience feelings of uncertainty, attempts to understand and find meaning, and tries to be supportive to their family members.

Surrendering to the journey for these close relatives meant they had to learn to adapt to the process. Similar to what Robinson, Carroll, and Watson (2005) found when they looked at the coping ability of a family affected by cancer, their coping ability was impacted by their ability to transition from the world before a cancer diagnosis to a world of cancer. Some of the results of this study found that coping with the journey for these close relatives meant a reliance on God and an embrace of their faith. Some of these close relatives relied heavily on their faith and their belief in God as a means of coping with the disease. They realized that surrendering to the journey meant they were ultimately not in control. This reliance on God may be used to further understand how close relatives find meaning in their experience and learn to adapt and cope throughout their journey. For others, coping came in the form of reliance on the doctors and healthcare staff to take care of their loved ones.

For these close relatives the process of s*urrendering to the journey* does not mean giving up or letting their guard down, it means recognizing that they are not in control; recognizing that they can't change the situation, the diagnosis, the cure, or the passing of the child. They realize that they are not the primary focus but they are a vital part in the process. They know that their presence matters; their support, their being there, their taking care of the family, their every little deed matters. They realize that the journey is part of the plan. They surrender to it because they accept it and they know that through it all, they have witnessed difficult times and many blessings, a life time of memories, family togetherness, reliance on God and others, and growth. They surrender and accept the journey no matter what the outcome; they will embrace it, because they have no other choice. Close relatives surrender to the journey because they recognize that through all that has been endured, a growth has emerged; an unforeseen strength in the parents, an unforeseen strength in their grandchild, niece, or nephew. They have witnessed an unending community of love and support and they realize that through all of the pain and suffering, love and joy, blessings and curses, that are one with the journey and so they surrender.

Finding Meaning

Close relatives in this study expressed struggling with both positive and negative emotions throughout their experience. However, because they felt unable to control their journey, part of being in control meant attempting to find meaning in their process. Through close relatives' questions of "why" would their relatives have to go through this painful process; they experienced various emotions. These questions continued to elicit feelings of helplessness, devastation, uncertainty, and general overall questions about how to cope. Through the struggle with these feelings close relatives began to identify the positives of their experience, which led them to find meaning. Santacroce (2002) found that feelings of anxiety and posttraumatic symptoms were experienced by parents. Close relatives in this study also experienced these feelings but to a lesser degree than the parents. A similar finding of the close relatives in this study was the anxiety and uncertainty that increased as the treatment came to an end. This finding was also similar to those of Stam, Grootenhuis, Brons, Caron, and Last (2006) who found that parents' anxiety was the greatest at the end of treatment. In addition to struggling with the negative feelings these close relatives expressed positive feelings as well. The strongest positive feeling expressed by these close relatives was that of hope. These close relatives believed that part of their job as caregivers was to keep hope and have faith. Serwint and Reeder (2009) had similar findings in their study of parents of children with cancer in which the parents felt obligated to be the bearers of hope even when all else failed. These close relatives took it upon themselves to never give up even when it looked like there was nothing more that could be done. These close relatives are impacted just as heavily as the parents with regard to hope, uncertainty, adaptation, stress, and coping. Their interaction with their family members during this process has an enormous impact on their functioning. Their interaction with healthcare figures is relatively from a distance because the focus is on the child and the parents. The close relatives were overall happy with the interaction of the healthcare professionals within the confines of their loved ones. Close relatives appear to recognize their value in the process, but they are filled with strong emotions similar to the parents. However, these parents and these children rely on these close relatives for support, so it is difficult for these close relatives to focus on their own needs when their loved ones rely on them for so much support. Who is there to support the caregiver?

Close relatives also recognized the strength of their loved ones and their ability to cope with the circumstances. This strength resonated with the close relatives and led them to find meaning amidst their traumatic experience. Close relatives also found meaning through their role as caregivers. The fulfillment of this role aided in their ability to make sense of their experience and to further define the meaning of how and why this could happen to their loved ones.

Furthermore, close relatives found meaning through their experience by focusing on things they had control over and letting go of the things out of their control. Through focusing on the things they could control, caregiving, never losing hope, and embracing each and every moment, meaning and importance of their journey was clear. They must find meaning in order to survive the experience.

Engaging in Dual Caregiving

Another part of the close relatives' attempt to exert over their process and find meaning was to engage in caregiving. All of the participants saw this as a primary role. They believed that being supportive and helping where needed were things they could provide. To be a witness to pain and suffering of their family members was unbearable and something they could not control. Through their caregiving efforts they found ways to be helpful and supportive; thus giving them some control. Most of these close relatives spent hours at the hospital being care givers to the child and to the parents. This type of family support was similar to other findings reviewed in the literature review and is crucial to overall adjustment (Fuemmeler et al., 2003; Knapp & Contro, 2009; McMenamy & Perrin, 2003). High levels of family support have been associated with strong family ties and adaptive coping skills (Trask et al., 2003). Increased family support allows for expression of negative symptoms and feelings (Fuemmeler et al., 2003). The ability to use this coping technique creates a pathway for better adjustment (Fuemmeler et al.). Another dimension to these findings is a gap in which caregivers who are close relatives must not only care for the child but are also caregivers of the parents; hence the term dual caregiving. The parents in this study expressed a reliance on their family members to help them through the process. They relied on the close relatives for support such as help with the care taking of their child, to cry to, to gain reassurance from, and to be there when needed.

Another issue that evolved from this study with regard to engaging in dual care-giving is that at times these close relatives were not sure of what to do or what to say to help their loved ones. These responses are similar to those of parents who reported being dissatisfied with the support they received, which increased their psychological distress (Hoestra-Weebers et al., 2001). Many of the close relatives reported that they felt unsure of what their loved ones needed. They were afraid to say the wrong thing or do the wrong thing for fear it may upset their loved ones. For these close relatives making sure they did the right thing to help alleviate stress instead of add to the stress was a primary focus. Patterson et al. (2004) found that parents sometimes viewed support from families as a source of relief and a source of strain. There were times when parents felt hurt by the insensitivity expressed by other family members. Yet, the primary resource that parents identified as being helpful was support from others. This was also confirmed in the responses of the parents in the Patterson et al.(2004) study who relied heavily on their close relatives to be care givers and sources of support during this process.

Embracing the Moment

Close relatives expressed a constant need to embrace the moment, to cherish the time they had with their loved ones and to make memories and connections with them. All of the close relatives stressed important events that they remembered that included their loved one. Two of the close relatives' journals included several pictures of moments that they cherish. These findings are similar to Meert et al. (2009) who that found that parents had to maintain a connection with their child through the palliative care process and beyond. Close relatives in this study shared specific situations in which they had a special connection with the child, whether it was an event that they always did at the hospital such as makeovers or playing towers, or a phrase that they always called their loved ones such as "little dawhlie." The little things that these close relatives embraced were things that they had control over that they could have an impact on, as one close relative so eloquently put it: “get involved and embrace each moment”.

Implications for Social Change

There are several avenues for potential change based on the findings of this study and the resulting theory of surrendering to the journey. As the close relatives progressed from the beginning of the journey to subsequent parts of their journey they began to focus on things they could control while letting go of the things beyond their control. This change in focus allowed them to begin to feel more in control of their experience, although those feelings of uncertainty still remained. Through their overall experience of surrendering to the journey; they found meaning, engaged in dual caregiving, and embraced moments. These areas were part of their overall process in which they found ways to exert control over this journey. Understanding the experiences of close relatives and recognizing that although different in some ways from other groups that have been researched they; still have unmet needs of their own. Their needs may be somewhat more complicated given that they are called upon to care for the children and their parents and that they are at times unsure of what supportive measures to provide. Being able to know what close relatives undertake in their experiences of palliative care opens the door for new programming in pediatric palliative care.

Close relatives in this study spent enormous amounts of time focusing on their loved ones. Time to develop their own coping skills and their own time to process their journey was overtaken by their caregiving roles. Providing opportunities for close relatives to share their experiences, to further understand their family members’ experiences and to engage in interactions that value their supportive efforts will in turn help the family as a whole. Fuemmeler et al. (2003) found that increased family support allows for expression of negative symptoms and feelings. Furthermore, teaching close relatives coping skills and positive interventions to help them manage their feelings and their role as dual caregivers will lead to less stress, more optimism and better adjustment to the disease and palliative care. In addition, these results would be helpful in educating the healthcare system about this population who has unmet needs but often is unrecognized in the focus of pediatric palliative care.

Recommendations for Action

There are many individuals and organizations that can benefit from the results of this study. Families who are involved in the pediatric palliative care process, health care agencies, hospice and palliative care agencies, and close relatives who have loved ones that are experiencing palliative care could all benefit from the findings of this study. Furthermore, close relatives and families that are dealing with a chronic family illness may also benefit from these findings. The results of this study lead to the following recommendations in pediatric palliative care:

- Implementation of programming within the pediatric palliative care and healthcare system to address close relatives including grandparents, aunts, and uncles of children in pediatric palliative care needs and provide relative information regarding supportive measures.
- Individual one to one or group forums must be made available for close relatives to access during and beyond their palliative care process. The focus of these forums should be giving value to their feelings, supporting their care giving duties, and providing supportive measures to their role in the process.

- Encouraging close relatives to utilize programming may be somewhat difficult at first because they are so set on being the care giver and ignoring their own needs for support. Creative strategies may be needed to ensure participation.
- Implementation of support groups for other close relatives who live far away through the Internet may be a viable way to help these close relatives find support and not feel as though they are giving too much time to focus on their needs versus their loved ones needs.
- Educating close relatives on how to cope and what to expect from their family members during this time, how their family members may respond to various situations, and how they should respond to them will be crucial components of this programming.
- Furthermore, pediatric palliative care programming must provide ways for these close relatives to be heard, to get their stories out. Finding ways to tell their story and to remember their loved ones must be part of any pediatric palliative care programming.
- Due to the richness of data obtained from the journaling process of this study, it is likely that this emotional disclosure should be part of pediatric palliative care programming for both close relatives and parents. Art programs for both parents and close relatives that allow for expressive and supportive avenues may be warranted.
- Implementation of programming based on this theory of surrendering to the journey that has supportive-expressive components for close relatives in dealing with other chronic health problems may prove beneficial.

I will attempt to share the information collected in this study by publishing in scholarly journals, presenting at conferences that involve psychosocial aspects of oncology, pediatric palliative care and other healthcare arenas. Attempts to disseminate findings to palliative care hospital programming and area palliative care agencies will be conducted.

Limitations

Interpretation of the findings of this study is bound by limitations of this study. First, the sample size is small and limited data collection. Limitations affecting the generalizability and validity of the study included the participants' retrospective self-reports of their experiences, which may have increased bias. Participants may have censored actions, thoughts, and feelings in order to present themselves in a more positive light. The participants who volunteered to be in this study were Caucasian; which means no other races/ethnic groups were represented. Furthermore, only 2 men participated, which also limits the results of this study in terms of gender. The study was also bound by recruitment of participants through a purposive and snowball sample. These types of sampling limit the generalizability of the results due to purposive and snowball samples consisting of participants that meet certain criteria. Therefore, the results cannot be generalized to other populations that fall outside of the criteria.

Research Recommendations for Future Studies

In this study I explored specific themes that emerged with close relatives and their experience of pediatric palliative care. As this study, only included nine close relative participants, it would be important for additional studies with more participants and/or quantitative studies to provide additional data regarding the theory of surrendering to the journey and close relatives' perspectives. Many ideas and themes emerged from this study that could be further examined:

- What are the differences between male close relatives perspectives compared to female perspectives with regards to palliative care?

- Are grandparents more heavily impacted by the experience than aunts or uncles?
- How does the implementation of support groups for close relatives affect their ability to cope and handle their care giving duties?
- Does the incorporation of journaling in pediatric palliative care programming provide an effective means for communicating thoughts, fears, and plans?
- Do other ethnic groups have the same experiences of pediatric palliative care?
- Does age of the grandparents, aunts, and/or uncles have an impact on perceptions of pediatric palliative care?
- Is the impact on close relatives different for those who live farther away from their loved ones?

The outcome of this study could have a great impact on the way we view the close relatives in pediatric palliative care. Longitudinal studies that evaluate close relatives over a period of years may be a useful tool in understanding how they adapt over time and how/if their perspectives change.

Reflections of the Researcher

I gained an increased understanding of what close relatives must undertake as part of their own processes. I am certain that these close relatives brought new meanings to the palliative care process and provided the opportunity for me to see the bigger picture. As a parent who has been through the most unimaginable pain of losing a child; a sense of respect and admiration for these close relatives experiences was realized through this study. The impact of a cancer diagnosis on a family is indeed immense, but the impact of the cancer diagnosis goes beyond the parents, the child and the siblings. Grandparents, aunts, and uncles also feel the impact and must develop ways to cope with their pain and suffering while being primary care givers to the parents of these children and secondary care givers to the children. The thoughts and feelings that were expressed by these close relatives were indeed touching and revealed that there is still so much for us to learn about pediatric cancer and palliative care.

I recognize that biases and opinions most likely played a role in how the data was collected and perceived. Due to my personal experience identification with information presented from the participants' stories brought back many memories and at times made it difficult to listen to them. Acknowledging one's biases, as Glaser and Strauss (1967) recommended is absolutely imperative in grounded theory research, if the researcher is going to maintain neutrality. Although a quantitative study may have been easier to accomplish, I believed that a grounded theory study was needed to substantiate a theory of close relatives and pediatric palliative care. Additionally, this subject matter lends itself to qualitative design due to its emotionality and richness of experience.

Summary

Pediatric palliative care efforts are on the rise. Increases in programming to address family needs have been substantiated. Means for effective coping and valuing of family members is an undertaking that must be addressed. Although, pediatric palliative care measures are being implemented at the time of diagnosis whether a cure is found or palliative measures are needed, the focus has been on the child and the immediate family members. However, as can be seen from the results of this study, close relatives are highly impacted by their own experience and need to be included in any and all programming that addresses the family's needs. Pain, suffering, uncertainty, hope, care giving, and reliance on God and others are all factors that affect the perspectives of close relatives. Healthcare programming cannot proclaim to be meeting the needs of families in the palliative care process if it does not contain specific programming for close relatives. The findings from this study have shown that close relatives are being impacted by their experience of pediatric palliative care. They have shared their stories, their emotions, and their journey. Therefore, it is our duty to listen and respond.

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APPENDIX A: COOPERATION LETTER

Kansas City Hospice and Palliative Care
9221 Ward Parkway
Kansas City, MO 64114-3332
(816) 363-2600

May 28, 2010

Dear Ms. Feyh

Based on my review of your research proposal, I give permission for you to conduct the study entitled,"Perspectives of Relatives in Pediatric Palliative Care: A Grounded Theory Approach," within the Kansas City Hospice and Palliative Care agency. As part of this study, I authorize you to interview participants and ask them to complete some of the questions in journal format. Individuals' participation will be voluntary and at their own discretion. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting.
I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,

Kelli R. Traylor, LMSW
Staff Development Specialist
Kansas City Hospice & Palliative Care
9221 Ward Parkway, Suite 100
Kansas City, Missouri 64114
816-276-2749
ktraylor@kchospice.org

APPENDIX B: INVITATION TO PARTICIPATE AND DESCRIPTION OF STUDY

Phone Call to Parents:

Hello, my name is Janelle Feyh, and I am a doctoral student at Walden University. I am conducting research on pediatric palliative care. My study involves the perceptions of grandparents, aunts, and/or uncles of children who are currently receiving pediatric palliative care services or have received them in the past.

Before, I meet with the grandparents, aunts, or uncles of these children. I will need contact information for these participants. In addition, in order to cover all aspects of this study, I would greatly appreciate your answer to one of my journal questions. I will provide you with the question and ask that you respond to in journal format and return it to me in 7 days.

Your participation is strictly voluntary and will be kept confidential. No other person will know your name or your information. If you at some point, you decide that you no longer wish to participate, you can withdraw at anytime. Please feel free to contact myself at 785-249-6991, or my chair, Dr. Ellen Levine at Ellen.levine@waldenu.edu at anytime for further information.

Thank you for your consideration to participate in this study.

APPENDIX C: PARENT CONSENT TO PARTICIPATE

You are being invited to take part in a study of pediatric palliative care. You were chosen for this study because you are a parent of a child who has cancer and is or has been in palliative care. As part of this study, information you provide to a journal entry will be utilized.

This study is being conducted by Janelle Feyh who is a doctoral student at Walden University.

Background Information: The purpose of this research study is to understand the experiences of close relatives who are involved in the pediatric palliative care process. Through this understanding we can obtain knowledge of the challenges that close relatives faced when living through this experience and ultimately impact the healthcare services that are provided in this field.

Procedures: If you choose to participate in this study you will be asked to:

- **Respond to one question in journal format and return the journal to the researcher within 1 week. You may choose to write, draw pictures or be creative by any means in your response to the question.**

Voluntary Nature of the Study: Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you wish to be in this study. No one at Kansas City Palliative and Hospice Care will treat you or your family members differently if you decide not to be in the study.

Risks and Benefits of Participating in the Study: It's possible that being in this study might make you recall unpleasant things about their experience with pediatric palliative care. A list of counseling services will be provided if participation in this study presents this need. This study might help others learn more about how the pediatric palliative care process can be improved for them.

Compensation: There will be no compensation for your participation in this study.

Confidentiality of Data: All data will be stored in a locked file cabinet and will be kept confidential. No one but the researcher will have access to identifying data.

Confidentiality: You may ask questions you have now or if you have questions later, you may contact the researcher via Janelle Feyh at 785-249-6991 or janelle.feyh@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-925-3368, extension 1210. Walden University's approval number for this study is **IRB will enter approval number here** and it expires on **IRB will enter expiration date.**

The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my relatives' involvement. By I am agreeing to the terms described above.

Printed Name of Participant

Date of consent

Participant's Written or Electronic* Signature

Researcher's Written or Electronic* Signature

Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

APPENDIX D: INVITATION TO PARTICIPATE AND DESCRIPTION OF STUDY (CLOSE RELATIVES)

Phone Call to Close Relatives:

Hello, my name is Janelle Feyh, and I am a doctoral student at Walden University. Your contact information was given to me by your family member. I am conducting research on pediatric palliative care. My study involves the perceptions of grandparents, aunts, and/or uncles over the age of 18, of children who are currently receiving pediatric palliative care services or have received them in the past.

This study is entitled: Perspectives of Close Relatives in Pediatric Palliative Care: A Grounded Theory Approach. It is hoped that the results of this study will improve services to close relatives who are involved in pediatric palliative care. Your participation is greatly appreciated.

Your participation is strictly voluntary and will be kept confidential. No other person will know your name or your information. If you at some point, you decide that you no longer wish to participate you can withdraw at anytime. Please feel free to contact myself at 785-249-6991, or my chair, Dr. Ellen Levine at Ellen.levine@waldenu.edu at anytime for further information.

If you are interested in participating in the study, you will need to sign a consent form to participate. You may return the consent form either in the mail or you may bring the signed form to me at the time of the interview.

Thank you for your consideration to participate in this study.

APPENDIX E: PARTICIPANT CONSENT FORM

You are invited to take part in a study of pediatric palliative care and close relatives. You were chosen for this study because you are a grandparent, aunt, or uncle of a child who has cancer and is or has been in palliative care.

This study is being conducted by Janelle Feyh who is a doctoral student at Walden University.

Background Information: The purpose of this research study is to understand the experiences of close relatives who are involved in the pediatric palliative care process. Through this understanding we can obtain knowledge of the challenges that close relatives faced when living through this experience and ultimately impact the healthcare services that are provided in this field.

Procedures: If you participate in this study you will be asked to:

- Participate in an hour-long audio-taped interview
- Complete journal entries to 2 questions through writing and/or pictures or drawings
- Tell me what your experience of palliative care is like for you.
- After initial data has been collected, additional questions may be needed to further clarify the data. This may take an additional 30 minutes to complete.
- Member checking-at the completion of the analysis the researcher will want to verify the interpretation of what was learned from the data presented. This will require that you meet with the researcher for an additional 30 minutes.

Voluntary Nature of the Study: Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you wish to be in this study. No one at Kansas City Palliative and Hospice Care will treat you differently if you decide not to be in the study. If you decide to be in the study now, you can still change your mind during the study. If you feel stressed during the study you may stop at any time. You may skip any questions that you feel are too personal.

Risks and Benefits of Participating in the Study: It's possible that being in this study might make you recall unpleasant things about your experience with pediatric palliative care. A list of counseling services will be provided if participation in this study presents this need. This study might help others learn more about how the pediatric palliative care process can be improved for you. The study will hopefully help us understand how grandparents, aunts, and uncles think and feel about things that are important to them at this time in their lives.

Compensation: There will be no compensation for your participation in this study.

Confidentiality of Data: All data will be stored in a locked file cabinet. Audio-recordings will be uploaded and stored through password protection. No one but the researcher will have access to identified data.

Confidentiality: You may ask questions you have now or if you have questions later, you may contact the researcher via Janelle Feyh at 785-249-6991 or janelle.feyh@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-925-3368, extension 1210. Walden University's approval number for this study is **IRB will enter approval number here** and it expires on **IRB will enter expiration date.**

The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By my signature I am agreeing to the terms described above.

Printed Name of Participant ______________________________

Date of consent ______________________________

Participant's Written or Electronic* Signature ______________________________

Researcher's Written or Electronic* Signature ______________________________

Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

APPENDIX F: INTERVIEW PROTOCOL

Greet the participant with a handshake and smile and thank him or her for participating. Sit where the participant would like to complete the interview.

Read the following script.
Thank you again for participating in this research study. As I informed you when I first contacted you about this project, my name is Mrs. Janelle Feyh and I am doing a project to learn about how close relatives experience palliative care with their child relative who has cancer. I am inviting you to participate in this study because you are a grandparent, aunt, or uncle of a child who has cancer and is currently/or has previously been in palliative care.
I am going to read the consent form with you. You can ask any questions you have before you decide if you want to do this project. I am a student at Walden University. I am working on my doctoral degree. I am also in private practice as licensed clinical psychotherapist.

If you agree to join this project, you will be asked to:
*Take part in this individual, private interview that will last about an hour
*Agree to have the interview recorded
*Tell me about what it was like (or is like) for you to be in the palliative care process.
*Answer questions truthfully, but you can choose to skip questions you do not wish to answer, or just answer as much or as little as you want.
* Respond to two questions in journal format.

Do you understand what I am asking you to do to participate in this study? (*If the participant says yes, continue reading the script. If the student says no or hesitates before answering yes, ask him or her, what is unclear to him and what questions he or she has. Explain the expectations again and ask if he or she understands them. Repeat this as necessary, then continue reading the script.*)
You don't have to join this project if you don't want to. If you decide now that you want to join the project, you can still change your mind later just by telling me. If you want to skip some parts of the interview, just let me know.

It's possible that being in this project might make you recall unpleasant things about your palliative care experience. You may tell me things that worry you. But this project might help you and others learn more about yourself and how to cope better during this time. The study will hopefully help us understand how you and other close relatives think and feel about the pediatric palliative care process. .
(*Pause here and ask the participant if he or she understands these potential risks and benefits. Ask if he or she has any questions before proceeding.*)

Everything you tell me during this project will be kept private. That means that no one else will know your name or what answers you gave. The only time I have to tell someone is if I learn that you want to take your life or take someone else's life, I am required by law to report this to the authorities. Also, if I learn that you have been abused physically, emotionally, or sexually or that you have abused anyone physically, emotionally, or sexually than I am also required to report this to Social and Rehabilitation Services.
You can ask me any questions you want now. If you think of a question later, you

can reach me at **785-249-6991** or my doctoral committee chairperson, Dr. Ellen Levine. If you would like to ask my university a question, you can call Dr. Leilani Endicott. Her phone number is 1-800-925-3368, extension 1210.
(*Ask the participant to sign the consent form and provide him or her with a copy.*)
Are you ready to begin the interview now? I am going to turn the recorder on and begin asking the questions.

Pediatric palliative care occurs when a child experiences a life-limiting illness. For the purpose of this study we will be discussing cancer. Palliative care is ensuring that the physical, emotional, and spiritual needs of the child and family members are met.

1.) What thoughts and feelings about your child, niece, nephew or grandchild did you have during the palliative care process?

    Follow-Up: How would you describe your relationship with your child, niece, nephew or grandchild during this time?

    Follow-Up: What people do you remember as being important to you during this time?

2.) What was the most difficult part of being in the palliative care process?

    Follow-Up: What important events do you remember about your experience?

3.) What persons or places do you remember as being significant during this time?

    Follow-Up: How did these persons or places help you cope during this difficult time?

The journal entry questions will include the following:

4.) What have you learned from the pediatric palliative care process?

5.) What do you think are the most important things I should know about your experience of palliative care?

Now that the interview is finished is there anything that you would like to ask me?
Thank the participant for the interview and state again that it will remain confidential.

APPENDIX G: JOURNAL PROMPTS

Parents of Child- Journal Prompt

1) What do you think are the most important things I should know about your experience of palliative care?

Close Relatives-Journal Prompt

1.) What have you learned from the pediatric palliative care process?
2.) What do you think are the most important things I should know about your experience of palliative care?

APPENDIX H: LETTER OF COOPERATION FOR CODER

You are being asked to be an additional rater in a qualitative grounded theory study. Inter-rater reliability increases the likelihood that there will be agreement among the coders. If you agree to be a coder for this study, you will be asked to sign a letter of confidentiality.

This study is being conducted by Janelle Feyh who is a doctoral student at Walden University.

Background Information: The purpose of this study is to understand the experiences of close relatives who are involved in the pediatric palliative care process. Through this understanding we can obtain knowledge of the challenges that close relatives faced when living through this experience and ultimately impact the healthcare services that are provided in this field.

Eligibility: A coder who has or had a child, grandchild, niece or nephew with cancer will be excluded from participating.

Procedures: If you agree to be a rater you will be asked to conduct the following:

- Thoroughly examine each interview protocol.
- Code the data.
- Return all data in a timely manner to the researcher.
- Maintain all information regarding participants' data confidential.

Voluntary Nature of Coding: You are being asked to be a coder for this study on a voluntary basis. Therefore you are under no obligation to agree to be a coder for this study.

Compensation: There will be no compensation for agreeing to be a coder for this study.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By my signature I am agreeing to the terms described above.

Printed Name of Coder	Stacie Bryant
Date of consent	11/29/2010
Coder's Written or Electronic* Signature	Stacie Bryant
Researcher's Written or Electronic* Signature	Janelle Feyh

Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

APPENDIX I: CONFIDENTIALITY AGREEMENT FOR CODER

Name of Signer: Stacie Bryant

During the course of my activity in collecting data for this research: Perspectives of Close Relatives in Pediatric Palliative Care: A Grounded Theory Approach.

I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant’s name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I’m officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: Stacie Bryant **Date: 11/29/10**

APPENDIX J: MEMBER CHECK FORM

Hello______________________.

I have finally come to the point in my research in which I am interested in your feedback of my preliminary findings. The following list summarizes the themes from all of the interviews I conducted. ***Please review and return this form to me by February 3, 2010.***

I have marked the subthemes that were present in your interview. If you would like to revise, add or delete the markings, please use the space to the right of the item to offer brief comments. I have provided additional space at the end of this form if you would like to provide an extended explanation for any of the items.

Major Thoughts and Feelings Described

- Feelings of hope and uncertainty
- Feelings of shock and devastation
- Feelings of helplessness and sorrow
- Feelings of a curse and a blessing
- Feelings of bewilderment
- Feelings of the unknown
- Question as to why this would be happening
- Question as to why this would happen to a child
- Question as to what you can do or how to help
- Recognizing the strength of the child and his/her parents

Major Thoughts Regarding the Most Difficult Part

- Watching them have to go through that pain and suffering
- Feeling helpless to do anything about it
- Seeing what it does to a family and how it changes them
- The initial diagnosis
- Wondering if it will come back
- The many medical treatments
- Watching them be sick
- The many hospitalizations and treatments they have to endure

Major Thoughts Regarding Your Role

- Be supportive
- Help anyway I can
- Be respite for the family
- Be there

- Pray for them
- Be Involved
- Making memories
- Living every moment with the child
- Recognizing the smallest of moments
- Building connections

Major Thoughts Regarding What Got You Through

- Reliance on God
- Never losing faith
- Keeping the hope
- Trust in the doctors
- Reliance on others for help
- Strength of the child
- Strength of the family
- Continued Prayer
- Finding meaning in your experience

Please circle a response to indicate your agreement with the above findings:

Mostly Agree	**Somewhat Agree**	**Agree**	**Disagree**	**Somewhat Disagree**	**Mostly Disagree**

If you are in disagreement with the above findings, please write your reasons below:

APPENDIX K: LIST OF COUNSELORS/SERVICE PROVIDERS

KeyPoint Counseling Services-
3101 Broadway Street, Suite 240, Kansas City, MO 64111
Phone: 816-561-5555

Diversity Counseling
4010 Washington Street, Kansas City, MO 64111
Phone: 816-756-3858

Rebecca Matthews LPC
4635 Wyandotte Center, Kansas City, MO 64112
Phone: 816-561-1200

Midwest Christian Counseling Center
4800 Main Street, Suite G29, Kansas City, MO 64112
Phone: 816-561-3726

Northland Counseling Services
4444 N. Belleview Ave, Kansas City, MO 64116
Phone: 816-453-2600

Family Conservancy
5424 State Avenue, Kansas City, KS. 66102
Phone: 913-287-1300

Riordan Kathleen
7301 Mission Rd. Prairie Village, KS. 66208
913-383-7882

CURRICULUM VITAE

Janelle Marie Feyh
3004 NE Kansa Trail
Topeka, KS. 66617
Phone: 785-286-7267
Janelle.feyh@waldenu.edu

Objective: To secure a career position in which my education, training and experience can be fully utilized.

Competencies:

- Conduct ethical and significant research
- Effectively lead groups of individuals to achieve goals and follow the mission/vision of the organization
- Self-starter and hard-worker
- Competent in working with people facing chronic health problems or various diagnoses
- Effective at presenting information in group/lecture format
- Competent in completing psychosocial assessments, psychological evaluations, and educational evaluations
- Dedicated to helping others and creating positive social change
- Strong supervisory/management skills and program development skills
- Organizational skills and effective time management
- Competent in developing staff development workshops

Education

Doctor of Philosophy Health Psychology Expected: May, 2011
Walden University, Minneapolis, MN

Dissertation Topic: Perspectives of Close Relatives in Pediatric Palliative Care: A Grounded Theory Approach
GPA: 3.92

Master of Science Clinical Psychology December, 1993
Emporia State University
Emporia, KS.

Bachelor of Arts Psychology May 1991
Washburn University
Topeka, KS.

RELEVANT PROFESSIONAL EXPERIENCE
Licensed Clinical Psychotherapist August 2007 to present
Janelle Feyh, LCP
5847 SW 29th Street
Topeka, KS. 66614
Job Duties:

- Conduct individual, group, and family therapy for children, adolescents, and adults
- Conduct psychological evaluations, learning disability evaluations, dyslexia evaluations, parenting assessments, gifted evaluations, and psycho-social assessments
- Developed treatment plans for various disorders and chronic illnesses
- Served as a resource for families, court officials and schools that helped children be more productive in these areas

School Psychologist (full-time, then part-time) August 2006 to present
Kaw Valley School District
St. Mary's, Kansas
Job Duties:

- Conduct psychological and educational evaluations which helped several children to obtain the necessary modifications and accommodations to become successful in the classroom
- Lead IEP teams that collaborated to develop individualized instruction for children.
- Conduct several presentations and workshops with a minimum of 40 individuals on mental health issues that helped many affect positive educational environments for children
- Collaborated with parents and teachers to design educational environments that meet the needs of children

Sabbatical during August 2003- to August 2006 while my then 2 ½ year old son battled AML (leukemia) and then passed away in July of 2005.

Executive Director May 2001- August 2003
Doorstep Inc.
Topeka, KS.
Job Duties:

- Responsible for all activities of this social service organization including working with the Board of Directors, running committees, preparing annual budgets, supervising employees and several volunteers, researching, applying, and writing grants
- Responsible for developing fund-raising activities and raising awareness of our mission at Doorstep
- Conduct community presentations on various topics including nonprofit organizations, mission of Doorstep, and community service
- During my tenure at Doorstep, I significantly increased our fund-raising, was able to obtain many grants, and increased awareness to the community. Through my tenure at Doorstep, I was able to increase our fundraising efforts by 50%
- Responsible for the day to day management of this nonprofit organization.
- Served on various communities throughout the organization

LICENSE

Kansas License: Licensed Clinical Psychotherapist: LCP #272

Other Experience

In addition, to my previous experience I have been involved in the mental health arena for over 20 years. I have worked as a psychologist in a community mental health center, and was a program director for a residential psychiatric center for youth.

Clinical Internship

Family Service and Guidance Center
325 SW Frazier
Topeka, KS. 66604

COMMUNITY SERVICE/VOLUNTEER SERVICE

Leukemia/Lymphoma Society	Annually since 2004
St.Jude Radioathon	Annually since 2004
St.Jude fundraising at College Campuses	Annually since 2004
Children’s Miracle Network	Annually since 2004
DMAN Hero Foundation (our son’s foundation)	Annually since 2005
Toy Drive for Kansas University Medical Center	July 2010

Publications:

Feyh, J. & Holmes, C. B. (1994). Use of the Draw-A-Person with conduct disordered children. *Perceptual and Motor Skills, 78*(3), 1353-1354.

Presentation/Workshop Topics

Attention-Deficit Hyperactivity Disorder: Help for the classroom teacher
Mental Health Issues in the Classroom
Developing Behavioral Interventions for Children with Special Needs
How to be an Effective Leader
Understanding the Therapeutic Relationship

Papers Written (Non-Published)

Feyh, J. (2007*). Disadvantages in the Healthcare System for Children with Cancer.* Unpublished Manuscript, Department of Psychology, Walden University, Minneapolis, MN.
Feyh, J. (2009). *Childhood Cancer: An Overview of Leukemia.* Unpublished Manuscript, Department of Psychology, Walden University, Minneapolis, MN.
Feyh, J. (2009). *Palliative Care Consultation for a Pediatric Cancer Unit.* Unpublished Manuscript, Department of Psychology, Walden University, Minneapolis, MN.
Feyh, J. (2009). *Psychoneuroimmunology and Cancer.* Unpublished Manuscript, Department of Psychology, Walden University, Minneapolis, MN.
Feyh, J. (2009). *Childhood Depression Inventory: A review.* Unpublished Manuscript, Department of Psychology, Walden University, Minneapolis, MN.
Feyh, J. (2009). *Attention-Deficit Hyperactivity Disorder: A Review of this Neurobiological Disorder,* Unpublished Manuscript, Department of Psychology, Walden University, Minneapolis, MN.
Feyh, J. (2010). *Ethical Standards for Prescribing Medication,* Unpublished Manuscript, Department of Psychology, Walden University, Minneapolis, MN.
Feyh, J. (2010). *ADHD and Nutrition,* Unpublished Manuscript, Department of Psychology, Walden University, Minneapolis, MN.

Honors and Awards

Psi Chi International Honor Society
Award for Children's Mental Health Program

Professional Affiliates

Student, American Psychological Association

Grants Received

The grants that I have written thus far in my career, occurred when I was the Executive Director of Doorstep. I received grants that included: United Way, City of Topeka, 20-30 Club, FEMA Grant, and various smaller grants.

Research Interests: I am very interested in childhood cancer research including pediatric palliative care, pediatric pain management, the effects of chronic illness on families, the effects of cancer on younger children versus older children, grief and bereavement, and psychosocial aspects of childhood cancer and chronic illness.

Teaching Philosophy: I believe that we are all life-long learners and that our quest for knowledge should remain throughout our lives. As a professor, I believe that my students and I are learning and growing together. Although, I am the teacher, there is a mentoring relationship in which I am there to help my students attain their goals by obtaining knowledge, research and writing skills. My role is to promote the field of psychology, to engage my students in their quest for knowledge, and to be a vehicle for which they obtain a higher degree. I believe that for each course I teach, I have learned as much or more than my students.

References:

Ellen G. Levine, Ph.D., M.P.H. — Dissertation Chair

Faculty, School of Psychology

College of Behavioral and Social Sciences

Walden University

155 Fifth Ave. South, Suite 100

Minneapolis, MN 55401

ellen.levine@waldenu.edu

Karine Clay PhD — Dissertation Committee

Part-Time Faculty

School of Psychology

College of Social and Behavioral Sciences

Walden University

Karine.Clay @waldenu.edu

Cooper B. Holmes — Thesis Chair/Professor
Emporia State University
1200 Commercial

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mberg@fsgctopeka.com

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PO Box 54
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