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Addressing Illness Suffering in Childhood Cancer: Exploring the Beliefs of Family

Members in Therapeutic Nursing Conversations

by

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Abstract

Children with cancer and their families experience physical, emotional, spiritual, and relational distress. Despite calls for comprehensive psychosocial intervention, family intervention research in childhood cancer is limited. Within this doctoral thesis, research findings from a family intervention study which qualitatively analyzed research interviews, and videotaped clinical sessions of therapeutic conversations (57 hrs) between nurse clinicians (3) and family members (18) who were experiencing illness suffering in childhood cancer are discussed. The research was guided by philosophical hermeneutics and process research. The therapeutic conversations were guided by the Illness Beliefs Model.

Family members suffered in relation to the loss of family normalcy, which reflected a spiritual anguish, and yearning for home. Parents suffered as they faced their inability to protect their children. Parenting practices, once taken-for-granted, became questioned, leading to a lack of confidence and understanding. Within the family unit, family members experienced physical and emotional separation and isolation. Diverse experiences of loss and grief within illness suffering were reported. These losses included the loss of family normalcy, physical, relational, and symbolic losses, anticipatory grief, illness survivor grief, and losses related to the death of fellow patients. The Dual Process Model of Coping with Bereavement is proposed as one conceptualization of grief that may be applicable for clinical intervention in childhood cancer.

The nursing interventions which helped to facilitate the lessening of illness suffering included bringing the family together for a therapeutic conversation, and the creation of a therapeutic space where suffering was called forward, borne, and shared

between family members, as well as between the nurse and family. As nurses invited

family members into a reflective, listening stance, they were assisted to hear one

another's illness testimonies, which invited new interpretations of suffering. Integral to

this intervention process was the nurse's presence, which was marked by the holding or

containing of suffering, an ethics of hearing, the receiving of illness testimony as gift, and

the opening of suffering to multiple interpretations through the offering of new,

facilitating illness beliefs. Questions and nursing responses that invited family members

to externalize the internalized questions and conversations that they were having, were

particularly helpful in lessening suffering.

Acknowledgements

As I come to write the acknowledgements for this doctoral thesis, I find myself returning in memory to recall so many different people who have stood beside me, and I feel incapable of fully expressing how thankful I am for the ways in which each of them have cared for, supported, and challenged me in the writing of this work. I was not prepared for what this journey would ask of me, how much it would test me, and how it would be impossible to reach the end without the strength of so many others. First I must thank the children and families who agreed to participate in this research study. Each of you so openly shared your experiences of living as a family in the midst of childhood cancer. In that sharing, you have challenged me, and taught me so very much. You have taught me about the illness suffering of childhood cancer, and how as nurses we might best intervene to help lessen that suffering. Because of the conversations we have shared, I now live differently in the world. I also would like to thank all of the children and families that I have come to know in my nursing practice. I feel honored to have met each of you, and to have walked beside you.

Dr. Janice Bell, my doctoral advisor, has supported me, and shared her expertise and passion for Family Systems Nursing. I am very thankful for her guidance, patience, and unfailing commitment to the advancement of this specialized area of nursing practice. Her editor's lens and critical analysis of my writing has been very much valued and appreciated.

Dr. Nancy Moules, a member of my supervisory committee, has shared her expertise and love of philosophical hermeneutics with me. A few years ago, she and Dr. Dianne Tapp introduced me to Gadamer's (1989) writing on philosophical hermeneutics,

too serious. I also thank those who have helped keep my body well during this writing: Mavis Wahl, a friend and wonderful massage therapist, as well as Jeff Mah, whose yoga classes and philosophical thoughts have given me strength and helped to ground me in so many different ways.

Dedication

This dissertation is dedicated to my parents, Audrey and John West.

Without their love and many sacrifices, this writing would not have been possible.

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CHAPTER ONE: INTRODUCTION TO THE RESEARCH INQUIRY

What does illness suffering come to render unspeakable for family members living in the midst of childhood cancer? What are the internalized, unspoken questions that family members ask themselves, as they experience physical, emotional, and/or spiritual suffering in living with childhood cancer? How can we come to understand the many changes in family life and relationships, when suffering comes to stand, threatens to cross, the threshold of childhood? How might nursing intervention more fully address the illness suffering of family members in childhood cancer? These are some of the questions that emerged from my nursing practice in pediatric oncology. They are the questions that called for a new conversation, a pedagogical exploration. These questions were laid at my feet, waiting for an unfolding, hoping for a renewal and discovery, a movement towards a more complete understanding. In the coming to these questions, unfairness and despair seemed to speak so very loudly. For of all the moments in life, childhood speaks of a time when the entrance of illness and suffering should be forbidden, a time when it is most unwelcome and unexpected, when there seems to be no acceptable explanation for its arrival, for the whispers of its voice.

What relevance might a research study about how to intervene with family members who are suffering in the context of living with childhood cancer have for nursing education, practice, and research? In 2010, the Canadian Cancer Society estimated that there would be approximately 1300 children between the ages of 0 and 19 years of age diagnosed with cancer annually (Canadian Cancer Society, 2010). The families of these children are given the devastating news that their child has cancer and will need to undergo intensive therapeutic treatment which may include surgery, radiation,

chemotherapy, and/or bone marrow transplantation (Canadian Cancer Society, 2008). Since the 1950s the rate of mortality for children diagnosed with cancer has decreased by more than fifty percent (American Cancer Society, 2006; Canadian Cancer Society, 2006). Yet, despite the remarkable clinical advances that have been made in the treatment of childhood cancer, for children over one month of age, cancer is still the leading cause of disease-related death (Statistics Canada, 2007). Further, with the marked improvement in clinical outcomes, the intense and complex nature of cancer treatment has also increased significantly. The Canadian Cancer Society (2008) has estimated that two-thirds of childhood cancer survivors have at least one chronic or late-occurring effect from the intense therapy they undergo, while up to one-third have a serious or life threatening complication related to cancer and/or its treatment.

The growing complexity of cancer treatment for children has brought with it an intensification of the distress experienced by children and families across the illness trajectory of childhood cancer. All family members face intense demands within the physical, emotional, and spiritual realms of this illness experience. The life-threatening aspects of this illness, as well as the intense and demanding nature of its accompanying symptom trajectory, have been shown to greatly affect the quality of life of both child and family (Björk, Wiebe, & Hallström, 2009; Eiser & Eiser, 2007; Hinds, 1990; Hinds et al., 2009; Moody, Meyer, Mancuso, Charlson, & Robbins, 2006; Patterson, Holm, & Gurney, 2004; Woodgate, 2001, 2003, 2005, 2006a, 2006b; Woodgate & Degner, 2002, 2003a, 2003b, 2004; Woodgate, Degner, & Yanofsky, 2003). Ill children and their families are forced over many months, and at times over many years, to endure painful procedures and treatments, as well as profound changes in family routines, relationships, and roles,

as they adapt to the demands of living in the presence of cancer (Björk, Wiebe, & Hallström, 2005, 2009; Clarke-Steffen, 1990, 1993, 1997; McCubbin, Balling, Possin, Frierdich, & Bryne, 2002; Patterson et al., 2004; Patterson Kelly & Ganong, 2011; Woodgate, 2001, 2006a, 2006b; Woodgate & Degner, 2003b, 2004; Woodgate et al., 2003).

In recent years, family-centered care has come to guide clinical practice with children and families in pediatric oncology centers across North America. Although this approach has been widely adopted and promoted within the field of pediatrics generally, the implementation of family-centred care has remained challenging. This has been partly due to unclear conceptual definitions, inconsistent implementation, as well as a lack of evidence-based practice models to assist nurses in the practice of family-centred care (Franck & Callery, 2004). In 2006, nursing scholars defined family-centered care

> …as a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all family members are recognized as care recipients. (Shields, Pratt, & Hunter, 2006, p. 1318)

How might nurses best care for all family members within the context of childhood cancer? Beyond understanding that all family members are the focus of their care, nurses need to be guided by evidence-based models of family assessment and intervention. Within this research study, the actual process of Family Systems Nursing intervention with families living with childhood cancer was studied through a hermeneutic interpretation of videotaped clinical sessions of therapeutic conversations, as well as qualitative research interviews conducted with the nurses and family members

after they participated in the therapeutic conversations. The family intervention was guided by the Illness Beliefs Model (IBM) (Bell & Wright, 2011; Wright & Bell, 2009; Wright, Watson, & Bell, 1996), an advanced nursing practice model for Family Systems Nursing. Within this research, Family Systems Nursing (Bell, 2009; Wright & Leahey, 1990) is defined in the following way:

> Family systems nursing can be conceptualized as focusing on the whole family as the unit of care. Concentration is on *both* the individual *and* the family simultaneously. The focus is always on the interaction and the reciprocity. It is not "either/or" but rather "both/and." Family systems nursing is the integration of nursing, systems, cybernetics and family therapy theories. (Wright & Leahey, 1990, p. 149)

The aim of this research is to gain a greater understanding of the illness suffering experienced by family members when a child is diagnosed with cancer, and to provide guidance about how nurses may intervene with the family, allowing illness suffering to be addressed in a more comprehensive manner.

The Research Questions

Based on the clinical practice of Family Systems Nursing that has emerged from the Faculty of Nursing at the University of Calgary, Lorraine Wright has articulated the importance of the internalized questions that family members ask themselves in the midst of illness suffering. She has suggested that family members who are suffering in the context of serious and/or life-threatening illness, ask themselves many questions within their internal conversations (Wright 2005, 2008), conversations which are often unshared, unspoken, and unheard. Wright (2005) has come to understand that these internalized

questions are the "entry points into the world of sufferers" (p. 155). Within the present research inquiry, there will be an exploration of the internalized questions that family members asked themselves in the context of living and suffering in the midst of childhood cancer.

Here then, are the research questions which guided this hermeneutic inquiry: What are the internalized questions that parents, ill children, brothers, and sisters ask themselves as a part of living with childhood cancer? How as nurses might we better attend to the illness suffering that is a part of the family experience of living with childhood cancer? This dissertation, particularly the findings which will be reported in chapters seven, eight, and nine of this thesis, are a response to these research questions. They do not represent the right response, or the only possible response, but one interpretation that may hold possibilities for guiding professionals in how to better encounter and address suffering within the clinical care of families who are living with childhood cancer.

The Bringing of Ourselves to the Call of the Address

Within hermeneutic interpretive inquiry, it is important that the researcher attends to how they were addressed by the research topic, why it is that this particular research topic, these particular research questions, have called out to the researcher, asking for an exploration. "Heidegger (1996) maintained that human life is not given to us as a phenomenon which requires our explication, but as a question, an address, as something which is revealing and concealing, coming and going, present and absent – and the work of hermeneutics is entering into the interpretation of things" (Moules, 2002a, p. 15). In this address, we find ourselves at the beginning of a quest, placed upon a path that may

allow us to draw forth the living interwoven layers of the question in their "full, ambiguous, multivocal character" (Jardine, 1992, p. 51).

One of the central characteristics of interpretation lies in historically effected consciousness (Gadamer, 1989), the tradition we are, the history that comes as context with the emerging creation of meaning. Heidegger (1996) introduced historicity, but it was Gadamer who took up this notion with a thoroughness of thought: he argued for our belonging to history, understanding temporality as the emergence of the past within the present. If we are to embrace hermeneutic inquiry, to answer the call of an address, to create a space for the hermeneutic imagination, history needs to be accounted for, we are asked to move to a place of acknowledgement and responsibility in this regard. Heidegger spoke to the forestructures we bring to the act of interpretation, and Gadamer (1989) similarly explored how understanding emerges in the presence of the prejudices or fore-meanings that we bring to consideration of the research topic. For Gadamer (1989) the "hermeneutical task becomes of itself a questioning of things" (p. 269): a questioning of the research topic and text which have engaged the researcher, but also a questioning of the fore-meanings that are brought into the research process.

> A person trying to understand a text is prepared for it to tell him something. That is why a hermeneutically trained consciousness must be, from the start, sensitive to the text's alterity. But this kind of sensitivity involves neither "neutrality" with respect to content nor the extinction of one's self, but the foregrounding and appropriation of one's own fore-meanings and prejudices. The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness

and thus assert its own truth against one's own fore-meanings. (Gadamer, 1989, p. 269)

In bringing our biases, beliefs, and fore-meanings into the research process, they can be accounted for responsibly, allowing the research process to open new questions and aspects of the topic, while allowing a challenging and transformation of the fore-meanings the researcher entered with. In experiencing the text's alterity, new understandings of the topic emerge, but also new understandings of ourselves and of the historical tradition that we, as well as the research topic, are embedded in. This responsibility for our biases and beliefs is what in part invites the questioning and interruption of the research topic.

The responsibility for the prejudices and historicity from which these questions emerged, involves a careful accounting for, a drawing forth of the prejudices or fore-meanings I bring as the researcher, which then makes possible a responsibility for them. From this a question arises: How do I understand that my practice and life drew me to this topic, what compelled me to search for a more complete understanding about illness suffering in childhood, and family life? Part of the answer may lay in my own experience with illness in childhood, and another may be found in my clinical practice experience.

To Begin With a Story Embedded in the Particular History I Call My Own

As a child, I was born with a genetically caused illness, a clubfoot, a deformity which involved the twisting of my left foot into an abnormal position. Although this illness did not bring the threat of death, it did bring into my life multiple surgeries and hospitalizations during childhood, as well as a growing sense of difference, an experience

of being set apart from other children living beside me in the world. Anger was also a part of this illness experience, as well as questions of why me and not the sister that came one year following my birth; questions emerged deep within, remaining unvoiced and unexplored. These were internalized questions, a dialogue that remained deep within, unspoken. This is one of the central aspects of the research topic: what are the internalized questions that family members ask in the midst of physical, emotional, and/or spiritual suffering? What remains unsaid, unexpressed, and unheard by others? In his discussion of philosophical hermeneutics, Grondin (1994) speaks of the "antiquated doctrine of the verbum interius: the "inner word" that is never spoken but nevertheless resounds in everything that is said" (p. 119).

In my own childhood, I came upon an experience of unfairness in life. Memories remain of throwing up in the worry of the surgery to come in the morning, nights of having to sleep in uncomfortable shoes connected by a metal bar, and the inability to wear high-heeled shoes during my teenage years. The questions that remained unanswered in my childhood, that came to live with me, still remain elusive in many ways, but what has come is thankfulness despite the difficulty. A belief now resides within me that the questions themselves have given me an incredible gift, a different understanding of life, maybe even an openness to the address of questions that might not have come, not in this particular way, if these experiences belonged to another.

I also come to this research with sixteen years of clinical practice with children and families living with serious and life-threatening illness. Within the fields of neonatal intensive care, pediatric oncology, as well as pediatric palliative care and grief support, I have had the honor to walk beside many children and families who have had to face the

most serious of childhood illnesses. As I have entered their lives, I have witnessed intense suffering and vulnerability, but also experiences filled with strength and joy. For an accounting of how suffering engaged me, I must turn and walk into my own past, into my nursing practice in pediatric oncology. There, I come to meet once more, a beautiful three year old girl who brought me gently, and with much love, to a place of haunting, questioning, anguish, and confusion in my relationship with suffering's voice. She and I came to know each other soon after I had begun practicing in oncology. I had met suffering before in nursing, but never in such a profound and calling way. She lived with cancer for a good part of the three and a half years she was given. Near the end of her life, she experienced such unrelenting pain that at times she would hold my hand, arch her back, pushing her head up against the crib rails at the top of her bed.

So many questions were raised for me in the relationship I shared with her, her family, and their suffering. The physical nature of her suffering mirrored for me the incredible emotional and spiritual anguish her family faced together. In that suffering, there was such little that made sense, such an unfairness and injustice. That unfairness, her suffering, continues to cry out for an answer, it is not content to remain a whisper. Even in this writing, these questions bring a physical heaviness upon my chest, like a tight constriction of the heart within; they have come to live with me in a deep and abiding way.

One night, as I was with her, suddenly and unexpectedly, she called out for her father. With incredible anguish and worry she shouted the words, "I've lost my daddy!" As I now reread these words, I am brought to remember my own father and mother, always beside me, loving me, standing with me as I too would throw up, full of worry

within my own experiences of illness. I knew they would always be there no matter what illness brought to me, and now here in this moment, I discover the unveiling of family deep in the midst. With some reassurances, this child's worry seemed to pass, and her father soon returned. Since that day, I have found myself haunted by those words, the desperateness about them. In the days, months, and years since her life ended I have returned to them more than once. Was this her way to express her anticipation of a final goodbye to those she loved in this life? How do we respond to these cries when they come, how can we begin to better recognize and attend to suffering? Is it possible to encounter these moments differently, to embrace the concealed, unspeakable, whispering voice of suffering?

Hermeneutics asks us to enter the storied existence of our lives; Smith (1991) offered that "we find ourselves, hermeneutically speaking, always in the middle of stories, and good hermeneutical research shows an ability to read those stories from the inside out" (p. 201). Dwelling with the particular nature, the uniqueness of this story may open a door to move into the heart of suffering, to give ourselves over to the voice that may have become unspeakable, hidden, yet still present in a profound and enduring way. It is important in this, to remember that our embrace of the particular, "the relationship between the instance and that to which it seems to bear a 'family resemblance' is always in a type of suspense. Interpretive inquiry does not wish literally and univocally to say what this instance is. Rather, it wishes playfully to explore what understandings and meanings this instance makes possible" (Jardine, 1992, p. 56).

This research path brings a promise, an opening that may allow us to come to understand suffering more fully, to live within for a time, the suspense that this instance

brings forward. The relationship that this story, this particular instance shares with suffering, is at its heart an interpretive one (Jardine, 1992). To embrace the suspense, to experience an unfolding into suffering, there must be a "living with this instance for a period of time in order to learn its ways: turning it over and over, telling and re-telling it, finding traces of it over and over again in what you read….This instance is not static but rather 'leads' somewhere" (Jardine, 1992, p. 58).

Frank (1992) suggested that suffering often becomes lost in research, that somehow we have found "ways to talk about situations in which people suffer without mentioning suffering" (p. 478). The aim of this research is to explicitly engage family member's experiences of illness suffering, and to come to a deeper understanding of how nurses might better address this suffering in the context of clinical care. It is within a hermeneutic research path that I have come home, found a place where the question that claims me may breath again: hermeneutics offers an engagement, an encounter, a possibility for us to explore our shared embodied vulnerability to suffering; the mutual need that is brought forth allows us to help one another (Frank, 1992), and in this way, may also lead to a path of new understanding, bringing an embrace of the suffering that lives here among us.

For Caputo (1987), suffering takes us to the edge of the abyss, and exposes the flux that lies beneath, ever present yet for the most part, hidden from view. Within human life, there are moments in which the "thin membranes of structures" (p. 269) we stretch over the flux, are worn through, leaving the surface with a "transparency that exposes the flux beneath" (p. 269). For Caputo (1987), "suffering exposes the vulnerability of human existence, its lack of defense against the play of the flux" (p. 278):

The face of suffering is a mask through which something deeper resonates, leaving its echo behind. Who or what is speaking here, what voice sounds through the face? Is it the cry of one who suffers, the breath of air he breathes, the spirit/ breath…What is stirring in these words? Whose voice speaks?...Is it no human voice at all but simply the echo of the world-play as it plays itself out, the rush of its winds? Is the human breath but a share of this cosmic whirl? When we put our ear to the human mask, as to a shell we find on the seashore, what roar do we hear? "Is it the soul which is speaking?"…The task of a radical hermeneutics is not to decipher the speaker beneath the mask but to alert us to the distance which separates them – and then to preserve and keep it open…finding a way through the flux…of keeping the play in play, of disrupting the attempt to arrest the play. Its work…is openness to the mystery. (Caputo, 1987, p. 290)

Entering the Path of Hermeneutic Interpretation: A Call to Genuine Conversation

The origins of a hermeneutic research approach are found partly in the Greek name hermeneus, which makes reference to Hermes, who within Greek mythology is known as the messenger of the gods, and protector of travelers. He has a mischievous and playful character, and also is known well for being a trickster and liar (Caputo, 1987; Grondin, 1994; Moules, 2002a). Hermes holds "the character of complication, multiplicity…irreverence…and disdain for rules; however, he is the master of creativity and invention. He has the capacity to see things anew and his power is change, prediction, and the solving of puzzles" (Moules, 2002a, p. 3).

David Smith (1991) posed an important question for me to consider as I contemplated the fit of a hermeneutic research path: "how is it that Hermes and I found

each other?" (p. 202). Part of my response to this question can be found in appreciating the important place that conversation and language hold within my Family Systems Nursing practice, the questions that have claimed me, and a hermeneutic research practice based on the philosophical thoughts of Hans-Georg Gadamer (1989).

For Gadamer (1989), the act of entering into genuine dialogue is marked in part by an intense sensitivity to language, an awareness of the living history that language brings. Further, when we enter a genuine conversation, we do not conduct it, but rather work to enter the play of the dialogue, to give ourselves over to it.

> We say that we "conduct" a conversation, but the more genuine a conversation is, the less its conduct lies within the will of either partner. Thus a genuine conversation is never the one that we wanted to conduct. Rather, it is generally more correct to say that we fall into conversation, or even become involved in it …No one knows in advance what will "come out" of a conversation. Understanding or its failure is like an event that happens to us. (Gadamer, 1989, p. 383)

These philosophical ideas speak to the research approach of philosophical hermeneutics, but they also speak to my clinical nursing practice, and who I have come to be in this world. I have always felt a discomfort in the professionalization of conversation within illness and health care. The professional stance of expertise can at times create conversations that come with unspoken intentions. When we choose to embrace a stance of 'expertise,' is there a refusal to remove ourselves from the center of conversation, and what might this mean for those who are ill; for children and families who suffer in the context of living with childhood cancer? To truly listen to another is such a very

complicated endeavor, there are so many ways that entering into conversation can become characterized by a taken for grantedness, forgetfulness, and at times a disrespectfulness of the other, an ingenuine presence.

The advanced clinical practice in Family Systems Nursing practice that I have studied in the context of this research thesis is guided by the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996). The IBM is partly informed by the writing of Maturana and Varela (1992), two Chilean neurobiologists. They have made an important distinction between two explanatory paths of listening for explanations: objectivity and objectivity in parenthesis (Maturana, 1988, 1998). When objectivity is placed in parenthesis, the idea that one reality exists independent of the observer is questioned. We come to understand that at once we are observing and participating in reality, that there is an "ongoing bringing forth of a world through the process of living itself….it is always in our co-existence with others that we are bringing forth reality" (Wright & Levac, 1992, p. 915). When objectivity is placed in parenthesis (Maturana, 1998) we move away from a place where we listen for whether or not what another says agrees with what I hold to be true; with this, the possibility for a genuine conversation (Gadamer, 1989) is created.

D. W. Jardine (personal communication, April, 2004) has suggested that in human life we are living an incredible lie: we have come to believe, to embrace and participate in a pretense of openness. "We want to hear from you" are the words that resonate from this place of pretense. At times, has this pretense of openness entered pediatric oncology and created a home for disconnection, a turning away rather than an embracing of the other who comes to meet us in practice? Have we refused to be engaged by the suffering inherent in illness? In considering what suffering has made unspeakable for children and

families in pediatric oncology, I come to wonder how the living in a pretense of openness has played out, has it invited silence in? If the words shared with families come with an embedded message that only certain kinds of conversations, language, and meanings have the right to be voiced, have we, without awareness, invited the silencing of suffering's call?

Yet, even as I commit these words to the page, I came face to face with one of my prejudices: a belief that engaging suffering in an explicit way will bring healing to experiences of suffering. Hermeneutics asks that I remain open to a questioning of my most strongly held beliefs. Could there be times when suffering would rather not come out of hiding, times when if given a choice, it would choose to live mostly at a distance? Are there times when we need to focus on a re-definition, or re-creation of life, joy, and hope for a new future rather than illness suffering? These questions are also important to hold onto within the process of this research inquiry.

Concluding Thoughts

This research study will explore the phenomenon of illness suffering in the context of childhood cancer, as well as family level intervention based on the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996). Having articulated the research questions that will guide the inquiry, in chapters two and three I will review the literature which is relevant to the research questions. I will argue that this research study extends nursing knowledge related to illness suffering and family intervention in childhood cancer by bringing an explicit focus on the phenomenon of illness suffering, and a qualitative exploration of hours of videotaped therapeutic conversations for the purpose of better understanding how to intervene and address the illness suffering of

family members in clinical nursing practice. This literature review will be followed by an exploration of some beginning efforts to research family level intervention within the field of childhood cancer. Also discussed, will be the qualitative program of research previously conducted on clinical intervention based on the IBM (Wright & Bell, 2009; Wright et al., 1996) at the Faculty of Nursing, University of Calgary. All of these findings will be employed to articulate the significance of studying family level intervention based on the IBM, within the specific practice context of childhood cancer.

In chapters four and five of this dissertation, I will situate the research within the philosophical stance of hermeneutics. There, I will further explore the ideas discussed by Hans-Georg Gadamer in his work, *Truth and Method* (1989). The research process will also be articulated, including a discussion of the clinical context, family intervention practice, participant recruitment, and process of analysis and interpretation. In chapter six, I will introduce the family members and nurse clinicians who agreed to participate in clinical intervention at the Family Nursing Unit (FNU), and in research interviews for this PhD dissertation. Within the next three chapters (seven, eight, nine) I will present the interpretive findings from this research study.

In chapter seven, I explore the profound changes to the roles, relationships, and routines in family life that follow a diagnosis of childhood cancer. Family suffering in relation to the loss of family normalcy and the loss of home, a loss of the grounding and rooting in human life will be discussed. The spiritual anguish and distress that lies underneath the surface of the loss of family normalcy will be a part of this discussion. In chapter eight I will present the complex and layered experiences of loss and grief that are a part of illness suffering in the context of childhood cancer. These include illness

grief, anticipatory grief, and what I have called the survivor grief of illness. I will suggest that there has been a disenfranchisement (Doka, 2002) of family experiences of grief within the context of living with childhood cancer, and that this disenfranchisement could be addressed by bringing an explicit focus on grief as part of clinical intervention with families in this clinical context.

In chapter nine, I will present the findings that explore what was helpful and not helpful for families, from the perspective of both the family members and nurses who participated in the clinical work. Central to this research inquiry is the following question: what difference does participating in a therapeutic conversation, based on the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996) make for children and families experiencing illness suffering in the context of childhood cancer?

This dissertation will conclude with a discussion which focuses on the application of these research findings, taking into account considerations for nursing practice, education, and research. Here, I will explore the need to enhance holistic nursing care for the entire family in pediatric oncology, and will conceptualize family intervention within this population as a practice in health promotion.

CHAPTER TWO: A REVIEW OF THE CHILDHOOD CANCER LITERATURE

Within this chapter I will review what is already known about illness suffering in the context of the family and childhood cancer. The literature reviewed includes research in which there was a focus on the illness suffering of family members, including parents, siblings, and ill children. Following a description of the research, I will critique the present state of this knowledge, and explore recommendations for further knowledge development. There will also be a discussion of how this research thesis, which qualitatively explored the process of family intervention in the context of illness suffering, may extend nursing knowledge in relation to the research topic. In the critique of the current research, I will discuss the need to move beyond descriptive, cross-sectional research which primarily focuses on the family by conducting data collection with one or two family members rather than the family unit. There also exists a need to move from descriptive research with families to research which is intervention-based, facilitating an exploration of both process and outcomes of family nursing intervention in the context of childhood cancer.

Illness Suffering During the Diagnostic and Initial Treatment Period

The Entrance of Childhood Cancer Brings the Loss of Normalcy in Family Life

In qualitative research, parents have reported experiences of grief, fear, denial, and shock upon receiving a diagnosis of childhood cancer (Björk, Wiebe, & Hallstrom, 2005; Chen, Chao, & Martinson, 1987; Clarke-Steffen, 1990, 1993, 1997; Fletcher, 2010; Kars, Duijnstee, Pool, van Delden, & Grypdonck, 2008; Kelly & Ganong, 2011; McCubbin et al., 2002; McGrath, 2001a, 2001b; McGrath, Paton, & Huff, 2004; Moreira & Ângelo, 2008; Nicholas et al., 2009; Patterson et al., 2004; Tarr & Pickler, 1999;

Wong & Chan, 2006; Woodgate 2001, 2006a; Woodgate & Degner, 2003a, 2003b, 2004; Yeh, 2003; Yiu & Twinn, 2001). The time of diagnosis has been reported to be particularly sensitive and difficult for families with a diverse structure, such as stepfamilies (Kelly & Ganong, 2011). Mothers and fathers have reported high levels of psychological distress following diagnosis (Dahlquist, Czyzewski, & Jones, 1996; Patiño-Fernández et al., 2008; Sloper, 2000b; Pai et al., 2007; Wittrock, Larson, & Sandgren, 1994), although levels of distress have been shown to decrease over time (Dahlquist et al., 1996; Pai et al., 2007; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006; Wittrock et al., 1994). Further, despite the decrease in parental distress in the years following treatment, a significant number of parents do continue to exhibit clinical distress, particularly those parents whose children relapse, and parents who experience significant psychosomatic symptoms at the time of diagnosis (Wijnberg-Williams et al., 2006). The intense emotion that follows the diagnosis of childhood cancer, as well as the need to understand a large amount of medical information, can make open communication between parents very difficult (Fletcher, 2010; McGrath, 2001a; Mercer & Ritchie, 1997). While handling the complex emotions within the diagnostic period, parents also struggle with attending to the intense needs and emotions of ill children and well siblings (Kelly & Ganong, 2010; Martinson, 1993; McGrath et al., 2004; Young, Dixon-Woods, Findlay et al., 2002), as well as extended family members (McGrath, 2001b; McGrath et al., 2004).

From her longitudinal qualitative research exploring symptom experiences across the childhood cancer trajectory, Woodgate (2006a) has articulated the core family narrative as: "life is never the same" (p. 11). This family experience of life being forever

and irrevocably changed was also evident in other research (Earle, Clarke, Eiser, & Sheppard, 2006; Fletcher, 2010; Sidhu, Passmore, & Baker, 2005; Woodgate & Degner, 2002, 2003b). At diagnosis, families faced a changed world, the world they once knew was shattered (Björk et al., 2005; Clarke, Davies, Jenney, Glaser, & Eiser, 2005; Woodgate, 2001, 2006a, Woodgate & Degner, 2003b, 2004; Young, Dixon-Woods, Findlay, et al., 2002). Families have reported losing the security, safety, and certainty which they took for granted prior to diagnosis (Björk et al., 2005; Chen et al., 1987; Lillrank, 2002; Moreira & Ângelo, 2008; Woodgate 2001, 2003, 2006a; Woodgate & Degner, 2002). Families have also reported that life was placed on hold; the normal life they had know previously was suspended with the entrance of childhood cancer (Björk et al., 2005; Earle et al., 2006; Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997; Fletcher, 2010; Fletcher & Clarke, 2003; McGrath, 2001a; McGrath, Paton, & Huff, 2005; Reay, Bignold, Ball, & Cribb, 1998; Woodgate, 2001, 2006a; Woodgate & Degner, 2002, 2004; Woodgate, Degner, & Yanofsky, 2003). Following diagnosis, rather than looking forward into the future, families learnt to focus on living one day at a time (Björk et al., 2005; Clarke-Steffen, 1990, 1993, 1997; Earle et al., 2006; Moreira & Ângelo, 2008; McGrath, Paton, & Huff, 2005; Woodgate, 2001, 2003; Woodgate & Degner, 2002, 2003b). Parents of childhood cancer survivors have retrospectively reported a similar loss of normalcy in family life during their children's treatment for cancer. Further, these families reported that:

>non-normality lingered for some due to uncertainties related to cancer. They
>
>talked about how cancer invaded everything about their lives and how they felt
>
>like they were *in a different world* – almost a *surreal experience*…like being

suspended in time and place. (Patterson et al., 2004, p. 397)

Part of the loss of normalcy in family life involves the transition to becoming patient-centered families. The ill child and cancer treatment become the central organizing force in family life. Typically, mothers have reported staying close to the ill child, providing care and comfort in the hospital, while fathers have returned to employment and assumed new roles at home which have included caring for well siblings and fulfilling household tasks (Björk et al., 2005, 2009; Fletcher, 2010; Koch, 1985; Leavitt et al., 1999; McCubbin et al., 2002; McGrath, 2001a; McGrath et al., 2004; Mercer & Ritchie, 1997; Nicholas et al., 2009; Patterson et al., 2004; Williams et al., 2009; Woodgate 2001, 2003, 2006a; Woodgate & Degner, 2004; Woodgate et al., 2003; Yeh, 2003; Young, Dixon-Woods, Findlay, et al., 2002). This family process of life becoming centered on the ill child has been described by McCubbin et al. (2002) as learning to "tolerate living as a split family" (p. 105). Woodgate (2006a) has suggested that there are distinct family units that come into existence; at times, particularly in the context of increased symptom distress, there is a "merging of the parents' (especially the mothers') and ill child's sense of self" (p. 11).

Clarke-Steffen (1990, 1993, 1997), in describing a model of family transition to living with childhood cancer, similarly discussed the central place of finding a new normal. Repeatedly within the literature reviewed, families have reported moving from a place of shock, denial, feeling overwhelmed, and hopeless to developing acceptance, and learning to live as normal a life as is possible (Björk et al., 2005, 2009; Earle et al., 2006; Fletcher & Clarke, 2003; Huang, Mu, & Chiou, 2008; Kars et al., 2008; Leavitt et al., 1999; Martinson, 1993; Martinson et al., 1995; McCubbin et al., 2002; McGrath, 2001a;

Patterson et al., 2004; Tarr & Pickler, 1999; Wong & Chan, 2006; Woodgate, 2001, 2006a; Yiu & Twinn, 2001). Within this new family life, parents have also described the complex and conflicting demands they faced in trying to balance multiple family needs during cancer treatment (Björk et al., 2005, 2009; Clarke-Steffen, 1990, 1993, 1997; Fletcher, 2010; James et al., 2002; Kars et al., 2008; Kelly & Ganong, 2011; McCubbin et al., 2002; McGrath et al., 2004, 2005; Mercer & Ritchie, 1997; Nicholas et al., 2009; Patterson et al., 2004; Svavarsdottir, 2005; Williams et al., 2009; Woodgate, 2001, 2006a; Woodgate & Degner, 2004; Young, Dixon-Woods, Findlay, et al., 2002).

Illness Suffering Across Different Phases of the Childhood Cancer Illness Trajectory

Multiple Family Losses: Individual and Relational

Described within the illness narratives of children and families living with cancer reported by Woodgate (2006a), was the experience of multiple family losses, which compounded the suffering that families experienced. Although every family experienced many losses, the character of those losses was unique to each family (Woodgate, 2006a). Parents have described the intense emotions experienced by the family in relation to their experiences of loss. These have included feelings of numbness, and devastation, uncertainty, as well as the sense of being overwhelmed. Also experienced were feelings of helplessness, a loss of control, fear that their child would die (Björk et al., 2005; Clarke-Steffen, 1990, 1993, 1997; Chen et al., 1987; Koch, 1985; Martinson, 1993; McCubbin et al., 2002; McGrath et al., 2004, 2005; Moreira & Ângelo, 2008; Nicholas et al., 2009; Patterson et al., 2004; Sidhu et al., 2005; Woodgate, 2001, 2006a; Woodgate & Degner, 2002, 2003b, 2004), and grief in relation to their child's pain/symptom distress and to physical losses such as hair and functional abilities (Björk et al., 2005; Chen et al.,

1987; Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997; Koch, 1985; Patterson et al., 2004; Woodgate, 2001, 2006a; Woodgate & Degner, 2003a, 2003b, 2004; Woodgate et al., 2003). Even following the completion of cancer treatment, parents continue to experience fears about the future and worries about the possibility of relapse (Fletcher, 2010; Patterson et al., 2004).

In Woodgate's (2006a) symptom experience research, families described their fear of the ultimate loss, which was the death of their ill child, but another very significant loss feared by all of the families, was the break-up of the family unit: "next to struggling to beat cancer, families found the struggle to keep the family together as one of the most difficult things about childhood cancer" (Woodgate, 2006a, p. 15). Other researchers have similarly described the challenge families face in attempting to keep the family unit together (McGrath, 2001a; Wong & Chan, 2006; Woodgate 2001, 2003, 2006a; Woodgate & Degner, 2003b).

Relationship strain and conflict. Within their experience with childhood cancer, family members have described a deterioration/change in known family dynamics, relationships, roles, and routines (Björk et al., 2005, 2009; Chesler, Allesewede, & Barbarin, 1991; Clarke-Steffen, 1990, 1993, 1997; Cornman, 1993; Fletcher, 2010; Freeman et al., 2000; Huang et al., 2008; Iles, 1979; James et al., 2002; Kars et al., 2008; Kelly & Ganong, 2011; Koch, 1985; Kramer, 1984; Martinson et al., 1995; McCubbin et al., 2002; McGrath et al., 2005; Nicholas et al., 2009; Patterson et al., 2004; Sargent et al., 1995; Sloper, 2000a; Williams et al., 2009; Woodgate 2001, 2006a; Woodgate & Degner, 2002, 2003a, 2003b, 2004; Woodgate et al., 2003).

Strain and conflict have been reported within the marital relationship (Björk et al., 2005; Chen et al., 1987; Cornman, 1993; Dahlquist et al., 1993; Fletcher, 2010; Fletcher & Clarke, 2003; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998; Jones & Neil-Urban, 2003; Kelly & Ganong, 2011; Leavitt et al., 1999; Martinson et al., 1995; McGrath, 2001a; Neil-Urban & Jones, 2002; Nicholas et al., 2009; Patterson et al., 2004; Reay, Bignold, Ball, & Cribb, 1998; Yeh, 2003; Young, Dixon-Woods, Findlay, et al., 2002), although conflicting reports do exist. In a longitudinal, prospective, quantitative research study examining emotional distress, coping style, and marital adjustment two and twenty months after diagnosis, there were no significant changes in marital adjustment over time, even with isolation of those couples who had marital difficulties at diagnosis (Dahlquist et al., 1996). Further, marriage has been shown to have a protective effect, and parents have reported that their spouse is one of their greatest sources of support as they face childhood cancer (Barbarin, Hughes, & Chesler, 1985; Chen et al., 1987; McGrath, 2001b; Mercer & Ritchie, 1997; Speechley & Noh, 1992; Yiu & Twinn, 2001). Other family members have also reported that they drew comfort from the strength of the marital relationship (Patterson et al., 2004; Tarr & Pickler, 1999). And some parents have reported that their marital relationship was actually strengthened over the course of the cancer experience (Brody & Simmons, 2007; Chen et al., 1987; Martinson et al., 1995).

Difficulty and loss have also been reported in parent-sibling relationships (Bendor, 1990; Björk et al., 2005, 2009; Chesler et al., 1991; Fletcher, 2010; Freeman, O'Dell, & Meola, 2003; Iles, 1979; Jones & Neil-Urban, 2003; Koch, 1985; Kramer, 1984; Leavitt et al., 1999; Martinson, 1993; McGrath, 2001a; McGrath & Huff, 2003; McGrath et al., 2005; Ow, 2003; Patterson et al., 2004; Rollins, 1990; Sloper, 2000a;

Sidhu et al., 2005; Williams et al., 2009; Woodgate 2001, 2006a, 2006b; Woodgate &
Degner, 2004; Young, Dixon-Woods, Findlay, et al., 2002), parent-ill child relationships
(Björk et al., 2005; Di Gallo, 2003; Enskär, Carlsson, Golsäter, & Hamrin, 1997;
Fearnow-Kenney & Kliewer, 2000; Freeman, O'Dell, & Meola, 2000, 2004; Kameny &
Bearison, 1999; Kars et al., 2008; Kelly & Ganong, 2011; Leavitt et al., 1999; Martinson
& Yi-Hua, 1992; McGrath, 2001a; Patterson et al., 2004; Stewart, 2003; Woodgate,
2001, 2006c; Young, Dixon-Woods, Findlay, et al., 2002), as well as in ill child-well
sibling relationships (Bendor, 1990; Björk et al., 2005; Di Gallo, 2003; Fearnow-Kenney
& Kliewer, 2000; Iles, 1979; Kramer, 1984; McGrath et al., 2005; Murray, 1998; Nolbris,
Enskär, & Hellström, 2007; Rollins, 1990; Sloper 2000a; Wang & Martinson, 1996;
Woodgate, 2001, 2006a, 2006b). Further, altered family communication and silence
about illness within family relationships has been shown to contribute to and exacerbate
the relationship changes between family members within childhood cancer (Bluebond-
Langner, 1978; Chen et al., 1987; Clarke et al., 2005; Clarke-Steffen, 1990, 1993, 1997;
Cornman, 1993; Horstman & Bradding, 2002; Kramer, 1984; Last & van Veldhuizin,
1996; Martinson & Yi-Hua, 1992; Martinson, Yin, & Yi-Hua, 1993; Martinson et al.,
1995; Murray, 1998; Wang & Martinson, 1996; Yin & Twinn, 2004; Young, Dixon-
Woods, Findlay, et al., 2002).

Financial strain. One further illness related loss that has recently begun to
emerge within the literature is the loss of financial resources and the financial strain that
comes with the diagnosis and treatment of childhood cancer (Brody & Simmons, 2007;
Clarke-Steffen, 1997; Fletcher, 2010; Heath, Lintuuran, Rigguto, Tikotlian, & McCarthy,
2006; Huang et al., 2008; Jones & Neil-Urban, 2003; Martinson et al., 1995; McGrath et

al., 2005; Neil-Urban & Jones, 2002; Nicholas et al., 2009; Patterson et al., 2004; Woodgate, 2001, 2006a; Yeh, 2003). Parents have reported that even ill children have expressed worries about the loss of family financial resources in the midst of cancer treatment (McGrath et al., 2005; Patterson et al., 2004).

Gender differences. Reay et al. (1998) have explored the gender differences which emerge for mothers and fathers in the care of children with cancer. These authors have suggested that "fitting childhood cancer into family life almost invariably results in women giving up paid employment, domestic responsibilities or both in order to care for the sick child" (p. 40). Men, for the most part, continue with their work and professional lives, in an effort to meet the financial needs of the family. They have reported that some men take refuge in their work, compartmentalize different aspects of their lives, and perceive the illness experience to have much less levity than mothers (Reay et al., 1998). Within this qualitative analysis, Reay et al. (1998) suggested that mothers therefore have much different illness experiences than fathers, and come to "'suffer' in a way fathers do not" (p. 42). In other research findings, fathers have articulated the sadness, guilt, and role conflict they experience from the division of their time between caring for their ill child, and the responsibilities they carry at work (Brody & Simmons, 2007; McCubbin et al., 2002; Woodgate & Degner, 2004). They have been found to be increasingly involved in caring for ill children (Brody & Simmons, 2007; McGrath, 2001a; McGrath et al., 2004, 2005; Nicholas et al., 2009; Woodgate, 2006a), and have reported a strengthening of relationships with family members as part of the childhood cancer experience (Brody & Simmons, 2007).

The Search for Meaning by Families in the Context of Childhood Cancer

Changed world views, as well as the search for explanations and meaning were processes that were reported repeatedly within the research reviewed. Families struggled existentially, and asked why this had happened to their child, and their family (Barbarin & Chesler, 1986; Björk et al., 2005; Chen et al., 1987; Clarke-Steffen, 1990, 1993, 1997; Earle et al., 2006; Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997; Hinds & Martin, 1988; Hinds et al., 1996; Kars et al., 2008; McCubbin et al., 2002; McGrath, 2001a; McGrath et al., 2004; Patterson et al., 2004; Sidhu et al., 2005; Wong & Chan, 2006; Woodgate, 2001, 2003, 2006a; Woodgate & Degner, 2003b, 2004; Yeh, 2003; Young, Dixon-Woods, Findlay, et al., 2002). Within the search for meaning, some parents described feelings of guilt (Chen et al., 1987; McGrath, 2001a; McGrath et al., 2004; Ow, 2003), blamed themselves (Bearison, Sadow, Granowetter, & Winkel, 1993; Martinson et al., 1995; Yeh, 2003; Young, Dixon-Woods, Findlay, et al., 2002), and questioned their ability to fulfill the parental role of protector (Chen et al., 1987; Nicholas et al., 2009). In qualitative research which explored the parental experience of a first cancer recurrence, assuming meaning was one of the processes that helped parents move through this painful illness event. Some parents came to understand "that there was a greater purpose, most likely spiritual, underlying the recurrence" (Hinds et al., 1996, p. 151).

Within the research reviewed, family members have reported that their spirituality, faith, and religious beliefs assisted them in their search for meaning (Barbarin & Chesler, 1986; Björk et al., 2005; Chen et al., 1987; Fletcher & Clarke, 2003; Huang et al., 2008; Martinson et al., 1995; Martinson et al., 1996; Mercer & Ritchie, 1997;

Nicholas et al., 2009; Patterson et al., 2004; Schneider & Mannell, 2006; Tarr & Pickler, 1999; Yeh, 2003). In addition to finding comfort and support from their spirituality, families have also reported losing their faith/spirituality, and questioning previously held religious and/or spiritual beliefs (Fletcher & Clarke, 2003; Martinson et al., 1996; Nicholas et al., 2009; Schneider & Mannell, 2006).

McCubbin et al. (2002) reported that families strived to find "new world views through their appraisal of the situation" (p. 109). Other researchers have similarly described a re-appraisal process, changed understanding, adoption of a new perspective and new priorities (Björk et al., 2005, 2009; Patterson et al., 2004; Wong & Chan, 2006; Woodgate 2001, 2006a). Families have articulated the importance of maintaining a positive/optimistic outlook, and fostering hope (Barbarin & Chesler, 1986; Björk et al., 2005; Brody & Simmons, 2007; De Graves & Aranda, 2008; Fletcher & Clarke, 2003; Huang et al., 2008; Nicholas et al., 2009; Patterson et al., 2004; Tarr & Pickler, 1999; Yeh, 2003). Similarly, Woodgate (2003) described how important it is that children and families "not give up the spirit" (p. 145); in order to get through the intense suffering of the cancer experience, it was essential that a "sense of spirit within the individual and family"(p. 145) was maintained.

The Importance of Family During the Struggle of Living with Cancer

Children living with cancer gain great strength from the support and presence of their families (Aamodt, Grassl-Herwehe, Farrell, & Hutter, 1984; Bearison, 1991; Björk, et al., 2005; Cantrell & Matula, 2009; Enskär, Carlsson, Golsäter, & Hamrin, 1997; Enskär, Carlsson, Golsäter, Hamrin, et al., 1997; Freeman, et al., 2003; Haase & Rostad, 1994; Hockenberry-Eaton & Minick, 1994; Martinson, et al., 1995; McGrath, et al.,

2005; Tarr & Pickler, 1999; Woodgate, 2001, 2003, 2006c; Woodgate & Degner, 2003b).

Even for adolescents, family, as well as friends and peer groups, are reported to be of

great importance, particularly during times of illness distress (Weekes, Kagan, James, &

Seboni, 1993; Woodgate 2006c). In her review of the qualitative research related to

children's' experiences with cancer, Woodgate (2000) has noted that critical to children's

perception of themselves is the way in which family and friends accept and react to them.

It is argued that children's ability or inability to "return to a normal way of life may be

more related to how children's family and friends adapt to the cancer" (Woodgate, 2000,

p. 218), than to how individual children adapt.

Illness Suffering in Childhood Cancer: Knowledge Limitations and Recommendations for Future Research

Research with Individual Family Members has been Misinterpreted as Family Research

Bell and Wright (2007) have highlighted the important contributions of Suzanne

Feetham (1984, 1990, 1991) and Catherine Gilliss (Gilliss, 1983, 1989, 1991; Gilliss &

Davis, 1992) in calling for a shift in nursing research from a patient-centered,

individualistic approach, with its associated focus on data collection from individual

family members, to family research which is characterized by a focus on the family unit.

In 1991, Feetham called for a clear distinction between family-related research and

family research: she asserted that family-related research focuses "on the relationship

between family members, relying on data derived from individuals" (Feetham, 1991, p.

55), whereas family research focuses the unit of measurement on the family unit. Within

family research, "the sequence or pattern of behaviours is examined…rather than the

presence or absence of a given behaviour" (p. 56). A further criterion described by

Feetham (1991) for evaluating family research was that it be clearly guided by a family conceptual or theoretical framework. Bell and Wright (2007) suggested that if nurses are to involve families in practice and research, they will "need to think about the interaction and reciprocity between health/illness and family functioning, the interaction between nurses and the families in their care, and also consider the larger systems within which families and nurses exist" (p. 3).

The research literature reviewed was comprised of primarily cross-sectional, descriptive, qualitative research studies. Despite the growing call for the delivery of pediatric care that is family-centered (Corlett & Twycross, 2006; Franck & Callery, 2004; Shields et al., 2006), this review of the literature provides evidence that the descriptive research emerging from within the field of childhood cancer approaches the study of the family by predominantly focusing on the perspectives of individual family members, even when samples include multiple family members in data collection (Björk et al., 2005; Chen et al., 1987; Huang et al., 2008; Koch, 1985; McCubbin et al., 2002; McGrath et al., 2004, 2005; Moreira & Ângelo, 2008; Nicholas et al., 2009; Patterson et al., 2004; Tarr & Pickler, 1999). Further, parents are often the focus of data collection, when the intended goal is to understand the 'family' experience (Heath et al., 2006; Kelly & Ganong, 2011; Leavitt et al., 1999; Martinson et al., 1996; Martinson et al., 1993; McCubbin et al., 2002; McGrath, 2001a; Patterson et al., 2004). Another limitation within this body of research is the predominance of mothers as participants when the intended sample is parents (Bearison et al., 1993; Enskär, Carlsson, Golsäter, Hamrin, et al., 1997; James et al., 2002; Koch, 1985; Martinson et al., 1995; McGrath 2001a, 2001b;

McGrath et al., 2004, 2005; Ow, 2003; Williams et al., 2009; Wong & Chan, 2006; Yeh, 2003; Yiu & Twinn, 2001).

A Need to Articulate Conceptual or Theoretical Family Frameworks

Within the research reviewed, there were very few studies that clearly articulated a family framework to conceptualize and guide the research process. Even when present, family theoretical/conceptual frameworks were most often mentioned or described in the literature review, with no clear linkage to study design, data collection, analysis or the report of findings. Family theoretical/conceptual frameworks that were reported throughout this review included the following: Family Management Style Framework (Alderfer, 2006; Deatrick & Knafl, 1990; Deatrick, Mullaney, & Mooney-Doyle, 2009: Deatrick et al., 2006; Knafl & Deatrick, 1990, 2003, 2006; Knafl, Breitmayer, Gallo & Zoeller, 1996; Knafl, Deatrick, & Gallo, 2008; Ogle, 2006; Thibodeaux & Deatrick, 2007), The Family Adjustment and Adaptation Response Model (Patterson, 1988), The Family Empowerment Model (Dunst, Trivette, & Deal, 1994), The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993, 1996), and The Contextual Model of Family Stress (Boss, 1988, 2002).

There were five research studies that clearly articulated a linkage between their research and a theoretical family framework (Björk et al., 2005, 2009; Clarke-Steffen, 1990, 1993, 1997; Kelly & Ganong, 2011; McCubbin et al., 2002; Patterson et al., 2004). Of these, Clarke-Steffen (1990, 1993, 1997) and Björk et al. (2005, 2009), were the only studies to have a sample which included ill children and siblings in addition to parents. Clarke-Steffen (1990, 1993, 1997) employed the Family Management Style (FMS) (Alderfer, 2006; Deatrick & Knafl, 1990; Deatrick, Mullaney, & Mooney-Doyle, 2009:

Deatrick et al., 2006; Knafl & Deatrick, 1990, 2003, 2006; Knafl, Breitmayer, Gallo & Zoeller, 1996; Knafl, Deatrick, & Gallo, 2008; Ogle, 2006; Thibodeaux & Deatrick, 2007) framework in her work but did note that there was no explicit intention to employ the FMS as a framework to guide the inquiry at the point of study design; only when the model of family transition to living with childhood cancer emerged, did the applicability of the research to Knafl and Deatrick's FMS framework become apparent (Clarke-Steffen, 1997). This is problematic, as the aim is for the conceptual framework to guide the entire research process. However, this research did clearly articulate the framework, and subsequently illustrated strong linkages between the research findings and theoretical concepts. This attention to linkage between research findings and theory has been described as a priority for family research (Larson & Olsen, 1990).

Björk and colleagues (2005, 2009) similarly connected their findings to the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993, 1996), but this only occurred near the end of the discussion. There was no relationship between the framework and research design or analysis of data, and very limited linkage to the findings. In another research study, Kelly and Ganong (2011) explored the shifting family boundaries experienced by stepfamilies after the diagnosis of childhood cancer. In their discussion, the researchers suggested that nurses employ the Contextual Model of Family Stress (Boss, 2002) in an effort to guide family interventions in relation to shifting and ambiguous stepfamily boundaries in the context of a childhood cancer diagnosis. The construct of boundary ambiguity, as well as family systems theory was also clearly present in the introduction, and conceptualization of this research.

The research conducted by McCubbin et al. (2002) focused on identifying family resiliency factors which were perceived as helpful by parents in the family management of childhood cancer. This study was clearly designed, guided, and linked its findings to the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993, 1996). Similarly, Patterson and colleagues (2004) showed a strong and direct linkage between research design, data collection, analysis, and report of findings to the Family Adjustment and Adaptation Response Theoretical Model (Patterson, 1988). Although both of these studies included only mothers and fathers in their samples, questions addressed the resiliency factors, strains, and resources experienced by multiple family members (including ill children and siblings), and attended to how resiliency factors, strains, and resources occurred at multiple system levels. For example, in the work of Patterson et al. (2004), strains and resources were identified at the level of the ill child, family, community, and health-care system.

Research Studies That Met the Criteria for Family Level Research

There were fourteen descriptive research studies in this literature review that included multiple family members within their sample (Bearison et al., 1993; Björk et al., 2005, 2009; Clarke-Steffen, 1990, 1993, 1997; Chen et al., 1987; Cornman, 1993; De Graves & Aranda, 2008; Enskär, Carlsson, Golsäter, Hamrin, et al., 1997; Freeman et al., 2003; Koch, 1985; Martinson, 1993; Martinson et al., 1995; McGrath et al., 2004, 2005; Tarr & Pickler, 1999; Woodgate 2001, 2006a; Woodgate & Degner, 2002, 2003a, 2003b, 2004; Woodgate et al., 2003). Of these fourteen research studies, only three (Clarke-Steffen, 1990, 1993, 1997; Cornman, 1993; Woodgate 2001, 2003, 2006a; Woodgate &

Degner, 2002, 2003a, 2003b, 2004; Woodgate et al., 2003) approached collection of family level data as defined by Feetham (1991).

The first was the qualitative, longitudinal research conducted by Clarke-Steffen (1990, 1993, 1997) which explored the family strategies used in response to the diagnosis of childhood cancer. Two individual descriptive interviews were followed by a third interview with the entire family group. Respondents included fathers (n=7), mothers (n=7), ill children (n=6), and siblings (n=12). The difficulty lies in the lack of a rationale for why only the third interview was done with the entire family; as well, there was no discussion of how this data was combined with data collected from individual family members or how it may have been analyzed differently. Clarke-Steffen (1997) noted that as part of the analysis of interview data, comparison was made between families at similar time points as well as within families, comparing sequential interviews.

Cornman (1993) quantitatively explored dyadic and family responses to childhood cancer as well as individual responses. All members of the family unit participated, including mothers (n=19), fathers (n=17), ill children, and siblings. Although the scales used to measure family environment, family communication, and family emotional tone were completed by individual family members, there was the attempt to obtain dyadic and family level data. Parents and children completed the Kinetic Family Drawings-Revised (KFD-R) (Spinetta & Deasy-Spinetta, 1981), as well as measures of family environment. Parents completed the Family Environment Scale (Moos, 1974), while ill children and siblings completed the Children's Version of the Family Environment Scale (Pino, Simons, & Slavinowski, 1984). These scales facilitated an exploration of family environment in terms of interpersonal relationships, family

organizational system maintenance characteristics, and directions of personal growth. In addition to these scales, parents completed the Dyadic Adjustment Scale (DAS) (Spanier, 1976), a measure of marital adjustment.

Woodgate's (Woodgate 2001, 2003, 2006a; Woodgate & Degner, 2002, 2003a, 2003b, 2004; Woodgate et al., 2003) research on the symptom experiences of children and families across the illness trajectory of childhood cancer also met Feetham's (1991) criteria of collection of data at the family level. In this prospective, longitudinal, qualitative research study, data was collected from ill children, siblings, and parents of 39 families. Interviews with family members were held individually, as well as with multiple family members. Data collection also included focus group interviews, and 960 hours of participant observation, which facilitated observation of the interaction of family members across the illness trajectory of childhood cancer. Also included in the sample were physicians, nurses, social workers, and nursing aides. They were observed as they interacted with a child or family during the periods of family participant observation, but were not formally interviewed.

Future Research: A Call for Longitudinal Research, Clearly Articulated Qualitative Research Methodologies, and Diversity in Sample Composition

This literature review also opens an important question: how is it that within the existing literature, the word suffering only very recently arises in published accounts of the illness experiences of children with cancer, their brothers, sisters, and parents? Human suffering in the context of childhood cancer appears to have been replaced by words such as symptom distress, adaptation, adjustment, parental distress, coping, and posttraumatic stress. These are words that may have been helpful in coming to an understanding of the experience of children and families in oncology, but they are

professional words, words that may not fit well for those whose experiences it is we study.

The question that has arisen in the process of this literature review is whether we have lost sight of the presence and intensity of human suffering, family suffering, and child suffering, within the field of childhood cancer. Until very recently, the word suffering has not been used to describe the illness experiences of children with cancer and their families. How is it that we have not noticed the absence of this word, despite the suffering that pediatric oncology nurses stand in the midst of? In the contemplation of these questions, it is important to understand that language holds a living character, it is not innocent, even in it's taken for granted character (Gadamer, 1989). In his philosophical writing on the practice of hermeneutics, Gadamer (1989) articulated the centrality of the word to human understanding and to scholarship within the human sciences:

> Every word breaks forth as if from a centre and is related to a whole, through which alone it is a word. Every word causes the whole of the view that underlies it to appear. Thus every word, as the event of a moment, carries with it the unsaid, to which it is related by responding and summoning. The occasionality of human speech…brings a totality of meaning into play, without being able to express it totally. (p. 458)

In the last ten years, research and literature within the pediatric oncology has started to reclaim the word suffering, invited it back into the world of childhood cancer (Fochtman, 2006; Lillrank, 2002; Woodgate, 2003; Woodgate & Degner, 2003a, 2003b). This opens the question of whether approaches to clinical intervention with families have

been insufficient to address the suffering that families live with. How might health care professionals better intervene to alleviate the illness suffering of children and families in the world of oncology care?

The need to account for family suffering across the illness trajectory of childhood cancer. One of the limitations evident in the review of this literature was the predominance of cross-sectional research studies. Emerging from this analysis was an understanding of the importance of family in the childhood cancer experience, as well as an appreciation for the process-orientated, developmental, and relational nature of family suffering in childhood cancer. One limitation of cross-sectional research is the inability to address the relational process of change over time. The illness trajectory of childhood cancer is not linear, but rather, it involves many different fluctuations and nuances, marked by frequent, repetitive courses of very intensive treatment. Periods of acute symptom distress are interspersed with intermittent periods of recovery. The outcome of treatment, the outcome of each day, brings great uncertainty to family life: this can include unexpected relapses, "sustained remission, long-term toxicities, or death from the illness or treatment" (Stewart, 2003, p. 394). There is a need to attend to the developmental process of this trajectory, as well as the interaction of the trajectory with family life, through more longitudinal qualitative research, and a diversification of data collection methods.

Researchers need to clearly articulate the qualitative research approach employed. Another limitation of the existing knowledge was the lack of clarity in regards to the specific research approach employed within the qualitative research studies. Many researchers identified their descriptive exploratory studies as qualitative

based on specific data collection methods and data analysis techniques; they often failed to specify any particular qualitative research approach/methodology (Enskär, Carlsson, Golsäter, & Hamrin, 1997; Enskär, Carlsson, Golsäter, Hamrin, et al., 1997; Freeman et al., 2000; Kameny & Bearison, 1999; Martinson & Yi-Hua, 1992; Williams et al., 2009), or the philosophical assumptions that guided their work (Björk et al., 2005; Clarke-Steffen, 1993, 1997; Enskär, Carlsson, Golsäter, & Hamrin, 1997; Enskär, Carlsson, Golsäter, Hamrin, et al., 1997; Freeman et al., 2000; Haase & Rostad, 1994; Moody et al., 2006; Stewart, 2003; Williams et al., 2009; Yin & Twinn, 2004).

There is a need for researchers conducting qualitative studies to attend to the articulation of both the research approach and/or the philosophical underpinnings employed in their work. Further, the predominant data collection strategy across these qualitative research studies was an individual interview. A diversification of data collection methods, with the inclusion of participant observation, informal interviewing, and focus groups, would enrich the existing knowledge, as evidenced in the work of both Clarke-Steffen (1990, 1993, 1997), and Woodgate (2001, 2003, 2005, 2006a, 2006b; Woodgate & Degner, 2003a, 2003b; Woodgate et al., 2003). Further, an expanded use of drawings and other creative activities may also assist researchers in coming to a better understanding of the illness experiences of family members in the context of childhood cancer. Initial efforts employing the use of drawing within the research process was evidenced in the work of Cornman (1993), Horstman & Bradding (2002), and Rollins (1990, 2005).

Need for diversity in research samples: Ethnicity, family composition, and diagnosis. Within the body of research reviewed, the ethnicity of family members was

not always articulated. When it was, samples were often composed of primarily

Caucasian participants (Barbarin & Chesler, 1986; Brody & Simmons, 2007; Clarke et

al., 2005; Clarke-Steffen, 1990, 1993, 1997; James et al., 218; Jones & Neil-Urban, 2003;

Patiño-Fernández et al., 2008; Patterson et al., 2004; Rollins, 2005; Sargent et al., 1995;

Williams et al., 2009; Woodgate, 2001, 2003, 2006a, 2006b, 2006c; Woodgate & Degner,

2002, 2003a, 2003b, 2004; Woodgate et al., 2003). However, there was a diverse

collection of international research articles, which included the following countries:

Brazil, China, Taiwan, Hong Kong, Korea, Singapore, Australia, England, the

Netherlands, Amsterdam, and Iceland.

 Within the research samples there was also a predominance of traditional, two

parent/caregiver families (Clarke et al., 2005; Clarke-Steffen, 1990, 1993, 1997;

Cornman, 1993; James et al., 2002; Kars et al., 2008; Koch, 1985; McCubbin et al., 2002;

McGrath, 2001a, 2001b; McGrath et al., 2004, 2005; Patiño-Fernández et al., 2008;

Patterson et al., 2004; Sloper, 2000b; Tarr & Pickler, 1999; Williams et al., 2009; Wong

& Chan, 2006; Woodgate, 2001, 2003, 2006a; Woodgate & Degner, 2002, 2003a, 2003b,

2004; Woodgate et al., 2004), and cancer diagnoses of leukemia or lymphoma (Chen et

al., 1987; Clarke et al., 2005; Clarke-Steffen, 1990, 1993, 1997; Earle et al., 2006;

McCubbin et al., 2002; McGrath 2001a, 2001b; McGrath et al., 2004, 2005; Tarr &

Pickler, 1999; Woodgate, 2001, 2003, 2006a; Woodgate & Degner, 2002, 2003a, 2003b,

2004; Woodgate et al., 2003; Yeh, 2003).

Conclusion: A Call to a New Kind of Research

 The illness and relational distress described by families experiencing childhood

cancer demands our attention in clinical practice, and calls for qualitative research

approaches that move beyond descriptive, exploratory, cross-sectional studies with individual family members. There is a pressing need to better account for the complex, reciprocal, and interactional processes that occur between family members and across the illness trajectory of childhood cancer. Family research which focuses on data collection and analysis at the level of the family unit, guided by clearly articulated theoretical family frameworks is urgently needed within the field of pediatric oncology and family nursing. Further, the description and design of qualitative research needs to be refined and described in a much more comprehensive manner.

Within this qualitative hermeneutic interpretation (Gadamer, 1989), there was an analysis of therapeutic conversations between nurses and family members who were suffering in the context of living with childhood cancer. The relational interaction that was a part of this family intervention was studied through an analysis of videotaped clinical sessions provided over many months and/or years, and through in-depth research interviews with both the family members and nurses who participated in the therapeutic conversations. Further, the research inquiry was clearly guided by theoretical family assessment and intervention models, which included the Calgary Family Assessment Model (Wright & Leahey, 2009), the Calgary Family Intervention Model (Wright & Leahey, 2009), and the Illness Beliefs Model (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996), an advanced practice nursing model for Family Systems Nursing. While multiple perspectives were encouraged in the research through the analysis of videotapes of the therapeutic conversations, as well as research interviews with family members and nurses, not all family members were able to participate in the research interviews which were conducted after the intervention process.

CHAPTER THREE: FAMILY INTERVENTION RESEARCH

The very heart, the essence of family nursing practice is the healing of the physical, emotional, and/or spiritual suffering that often accompanies family member's experiences of illness (Bell & Wright, 2007). Within Family Systems Nursing practice, there is a recognition that nurses need to understand and address complex and layered relational interactions between family members and illness, the nurse and the family, as well as interactions with larger systems, such as the health care system (Bell & Wright, 2007).

The Family Nursing Unit (FNU) (1982 – 2007) was an extraordinary clinical practice unit at the Faculty of Nursing, University of Calgary that offered assistance to families who were experiencing physical, emotional, and/or spiritual suffering in relation to their experiences with illness (Bell, 2008; Wright, Watson, & Bell, 1990). Within this practice unit, graduate nursing students (masters, doctoral) and faculty who brought theoretical and clinical expertise in family systems nursing intervention, worked together with families to explicitly address illness suffering through family level intervention based on the Calgary Family Assessment and Intervention Models (Wright & Leahey, 2009), the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996), and the Trinity Model (Wright, 2005). This unique practice setting afforded graduate students the opportunity to witness, participate in, and gain clinical expertise in entering therapeutic conversations with family members. The clinical setting included an interview suite with a one-way mirror, and telephone intercom system which facilitated live supervision by a highly expert faculty member, who supported and worked with each graduate nursing

student and family within a team of nurses (Bell, 2008). Further, each family, graduate

nursing student, and nursing team member who came to the FNU to participate in

therapeutic conversations, were asked to consent to the videotaping of clinical sessions

for the purpose of future education and research (Bell, 2008). This afforded the creation

of an extensive database of videotaped clinical intervention and documentation for future

research and education.

This thesis is part of a program of research emerging from the FNU, leading to a

hermeneutic interpretation of clinical intervention specifically focused on understanding

and lessening the illness suffering of family members within the area of childhood

cancer. Prior to exploring the research that has emerged from the FNU previous to this

research thesis, I will review the family intervention research which has begun to emerge

within the field of childhood cancer.

Family Intervention Research

Family intervention in the context of physical illness has been an expanding area

of clinical specialization, and as such, the effectiveness of family intervention approaches

in relation to specific illnesses, adult and pediatric, has been increasingly growing over

the last ten years (Campbell, 2003; Chesla, 2010; Wiehs, Fisher, & Baird, 2002). In 2002,

Weihs and colleagues explored the linkages between family relationships, disease

management, and chronic disease management. Within that report, family interventions

were classified into different categories which included: psychoeducational intervention,

family relationship-focused intervention, and family therapy. Within the field of

childhood cancer, Weihs et al. (2002) reviewed two randomized trails within the

psychoeducational category; both centered on increasing parental coping in relation to the

stress of childhood cancer (Hoeksatra-Weebers, Heuval, Jaspers, Kamps, & Klip, 1998; Jay & Elliott, 1990). Only in Hoekstra-Weebers et al.'s (1998) research was there a demonstration of differences in parental distress, and no differences in patient distress were observed. In the family relationship-focused category, Weihs et al. (2002) reviewed Kazak et al.'s (1998) use of a cognitive-behavioral, family-orientated intervention with parents which focused on children's distress in relation to painful/distressing medical procedures. In the context of a randomized intervention design, which included a focus on parental-ill child interaction during procedures, lower distress in children was reported by mothers, fathers, and health care professionals. Also reviewed was Kazak et al.'s (1999) pilot of a multifamily group intervention for families of childhood cancer survivors. Here a pre-post design, rather than a control group was used to measure the reduction of posttraumatic stress symptoms in adolescent cancer survivors and members of their families. These researchers were able to demonstrate a decrease in posttraumatic stress and anxiety for adolescent survivors, siblings, and parents.

Recently, Catherine Chesla (2010) reviewed existing meta-analyses of randomized control trials which examined the effectiveness of family intervention research in chronic illness and offered her synthesis of these findings. This overview provided evidence supporting the effectiveness of family interventions in comparison to medical care alone, and additionally, there were studies which showed family interventions to be more effective than individually-focused psychosocial interventions. The only meta-analyses from the field of pediatric chronic illness focused on childhood obesity and Type 1 diabetes. Within childhood obesity, there was even stronger evidence than within the adult literature for the effectiveness of family interventions versus other

psychosocial focused interventions. Clearly more efforts need to be made to document and test family interventions with families who have a child living with chronic and life-threatening illness.

The Family Systems Nursing framework articulated in the Calgary Family Assessment Model (Wright & Leahey, 2009), Calgary Family Intervention Model (Wright & Leahey, 2009), and Illness Beliefs Model (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996) might offer new possibilities for clinical practice with families experiencing childhood cancer. These theoretical and clinical practice models are particularly appropriate for the study of illness suffering in the context of childhood cancer, as they bring an explicit focus to recognizing strength and resilience in families, as well as working to alleviate the illness suffering that family members live with in the context of chronic and life-threatening illness (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996). Further, the models focus on the family as system, as well as the interaction of the family system with larger systems such as the complex health care system which children and families must navigate in the context of cancer treatment. Also of importance is the attention these models bring to understanding the reciprocal interaction between family and illness.

The IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996) provides a practice guide for exploring, and challenging the meanings and beliefs that family members hold in the context of illness. In Woodgate's (2001, 2003, 2006a, 2006b; Woodgate & Degner, 2002, 2003a, 2003b, 2004; Woodgate et al., 2003) recent research on the cancer symptom trajectory as experienced by children with cancer and their families, the exploration and understanding of the beliefs/meanings associated with the

physical suffering of this illness experience, has been shown to be an integral, yet poorly addressed aspect of the provision of care for children and families living with cancer. Further, some of the posttraumatic stress research in childhood cancer has illustrated a need to better address the parental perceptions and beliefs about threat to life and treatment intensity (Best, Streisand, Catania, & Kazak, 2001; Kazak et al., 1998, 2004). Researchers have called for clinical intervention with focuses on addressing the illness beliefs of parents within the survivor population, as well as those families of children currently receiving cancer treatment (Best et al., 2001; Kazak et al., 1998, 2004).

Family intervention research has gradually emerged in childhood cancer over the last fifteen years (Kazak, 1997; Kazak et al., 1999; Kazak, et al., 2004b, 2005b). Future research with this population of families needs to shift from description of family response to childhood cancer into qualitative process intervention research with families (Bell & Wright, 2007; Greenberg, 1986, 1991; Greenberg & Pinsof, 1986; Lebow, 1996; Pinsof, 1989; Pinsof & Wynne, 2000), which focuses not only on the individual perspectives of ill children, siblings, and parents, but the interactional processes they share with one another, illness, as well as the health care professionals involved in their care during the very process of intervention. The field of family process research (Greenberg, 1986, 1991; Greenberg & Pinsof, 1986; Lebow, 1996; Pinsof, 1989; Pinsof & Wynne, 2000) comes to the discipline of nursing from the field of psychotherapy. It offers nurses a different research path, a path that may allow an exploration of the complex interactions between families and nurses, while simultaneously building knowledge which will enhance nurses' understanding of and intervention with families who are suffering in the midst of childhood cancer. Within this research, family clinical

intervention guided by the IBM (Wright & Bell, 2009; Wright et al., 1996) was studied by employing process/progress research (Greenberg, 1986, 1991; Greenberg & Pinsof, 1986; Heatherington, Friedlander, & Greenberg, 2005; Pinsof et al., 2009; Lebow, 1996; Pinsof, 1989; Pinsof & Wynne, 2000) and philosophical hermeneutics (Gadamer, 1989).

Family Intervention Research Within the Field of Childhood Cancer

Ann Kazak, a pediatric psychologist at the Children's Hospital of Philadelphia has adopted a family systems theoretical framework for the clinical assessment and intervention with families in childhood cancer, as well as for the rigorous evaluation of these approaches through research (Kazak, 1997, 2005; Kazak, Simms, & Rourke, 2002; Kazak, McClure et al., 2004; Kazak et al., 2007, 2009). In discussing the research priorities for family research in childhood cancer, she suggested that within the call for more effective clinical intervention at the family level, it is essential that approaches found helpful in research studies be translated in practice settings (Kazak, 2005). Kazak (2001) has emphasized the complex, multisystemic, and dynamic nature of comprehensive psychosocial care for the families of children who have been diagnosed with cancer. Within the field of childhood cancer, there has been growing interest in employing a posttraumatic stress framework for understanding the long-term psychological impact of childhood cancer (Brown, Madan-Swain, & Lambert, 2003; Kazak, Alderfer, Rourke et al., 2004; Kazak, Alderfer, Streisand et al., 2004; Kazak et al., 1997, 2007; Manne, Duhamel, Gallelli, Sorgen, & Redd, 1998; Manne et al., 2002). It has been suggested that a childhood cancer diagnosis and its subsequent treatment demands, evoke family responses similar to those exhibited in the context of other types of traumatic life events (Kazak, 2001).

In a study of 300 adolescent and child cancer survivors and their families, which used a comparison group of unaffected children, Kazak and her colleagues reported the presence of posttraumatic stress symptoms within family members; these being most prevalent in the mothers and fathers of childhood cancer survivors (Kazak et al., 1997). They have also reported findings that provide support for a relationship between posttraumatic stress symptoms and disease, treatment characteristics, as well as family and social support variables (Kazak, 2001; Kazak et al., 1997; Stuber et al., 1997). From this research program, Kazak has emphasized the importance of a family orientation to intervention practice and research in pediatric oncology, and with her colleagues, has developed a manualized intervention, the Surviving Cancer Competently Intervention Program (SCCIP) (Kazak et al., 1999; Kazak, Alderfer, Streisand et al., 2004). This intervention, a one day, four session family intervention program combining cognitive-behavioral and family therapy approaches, has been studied in a randomized clinical trial that evaluated the intervention with adolescent survivors of childhood cancer, their mothers, fathers and siblings (Kazak et al., 2004b). Within the treatment group of this randomized control trial, there were significant reductions in the intrusive thoughts experienced by fathers, as well as significant reductions in the arousal reported by adolescent cancer survivors. Kazak suggested that this data provides support for brief family level interventions for the reduction of post-traumatic stress symptoms, as well as additional support for the importance of psychosocial intervention with multiple members of the family (Kazak, Alderfer, Streisand et al., 2004).

Building on this work, this manualized family intervention was subsequently adapted for families of newly diagnosed children within pediatric oncology. Nineteen

families (38 caregivers) were assigned randomly to the treatment or usual psychosocial support group. Pre- and two-month post intervention assessments were conducted with state anxiety and posttraumatic stress symptoms as measured outcomes. The report of pilot study findings indicated reduced anxiety and parental posttraumatic stress symptoms (Kazak, Simms et al., 2005). One of the limitations of this latest program of study of family systems intervention is the exclusion of diagnosed children or siblings from the interventional and research process. Intervention with primary caregivers is being cited as support for continued intervention work and research at the family level. Another limitation is the framing of childhood cancer as a series of traumas. Kazak is a strong and persistent advocate for family systems intervention approaches which are competency and strength based (Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Kazak et al., 2002), yet has adopted a psychopathological framework in conceptualizing cancer as trauma, and the suffering exhibited by families who face the diagnosis of childhood cancer as posttraumatic stress (Kazak, 2001; Kazak et al., 1997, 2007; Kazak et al., 1999; Kazak, Alderfer, Rourke et al., 2004; Stehl et al., 2009).

Family Intervention Research: Hermeneutic Interpretations of the Process of Change

The field of process/progress research (Bell & Wright, 2007; Greenberg, 1986, 1991; Greenberg & Pinsof, 1986; Heatherington et al., 2005; Lebow, 1996; Pachankis & Golfried, 2007; Pinsof, 1989; Pinsof & Wynne, 2000; Pinsof et al., 2009) comes to the discipline of nursing from the field of psychotherapy. It offers nurses a different research approach, one that can help facilitate a qualitative exploration of the complex relational interactions that occur between families and nurses in practice. Traditionally, family intervention research has been framed within a quantitative paradigm, in which

measurements of illness and family variables occurs prior to and following the intervention period. Process/progress research is a very different approach which focuses on an actual exploration and examination of clinical practice, facilitating understanding about the very process of change in the context of intervention. This approach is unique, underutilized, and offers new possibilities for the development of qualitative family research studies. Process research may allow the relational practices shared between family members and nurses to become more visible and understood for further clinical practice application.

Qualitative hermeneutic interpretation is one research approach seen to be particularly suited to studying caring practices, both through the observation of practices and research interviews (Kesselring, Chesla, & Leonard, 2009). Family scholars have also acknowledged how highly complex this type of research endeavor is:

Observing in…community practice settings allows the ineffable yet skillful practices of nurses to be observed with the press of the situation intact. The contextual features of situations that draw forth practices are present for observation if the researcher has the appropriate sensibility to perceive them… Observation, while providing openings on unfolding practices that others forms of research engagement simply can't provide, remains a complex endeavor. (Kesselring, Chesla, & Leonard, 2009, p. 16)

Within this qualitative research study, hermeneutic interpretation and a process research approach made it possible to explore the very process of change (Pinsof, 1989) inherent in the videotaped therapeutic conversations shared by nurses and families, based on the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996). Here, the focus

was on the analysis of many hours of videotaped clinical work, and the collection of data from family members and the nurses who participated in the process of clinical intervention (Bell & Wright, 2007). The unique clinical practice setting of the FNU facilitated the use of a process research approach, through the provision of interview rooms with one-way mirrors, call-in telephones, videotaping equipment, and live supervision from expert nursing faculty/scholars in Family Systems Nursing (Bell & Wright, 2011).

Some researchers might argue that this is not family intervention research, given how different the approach is from the more traditional pre/post quantitative measurement-based conceptualizations of research with an intervention focus. But process research challenges the need for a singular focus on the outcome of clinical intervention, the results of change; instead, it invites an exploration of the very nature or process of change. This approach explores the beginning and end points of change, but simultaneously calls for an understanding of the processes that led to the change between those points (Greenberg & Pinsof, 1986). Process research does not bring a singular focus on either the family or clinician system, but is rather relational in nature: the aim being an understanding of how the interaction between family and clinician systems leads to therapeutic change (Greenberg & Pinsof, 1986). The process and results of intervention are not conceptualized as distinct entities, but rather are understood as standing in relation with one another, a relation that is circular, reciprocal, and progressive in nature.

It is important to note that this research approach has not developed significantly since the pioneering work of Greenberg & Pinsof (1985); large research programs in family therapy have not attended significantly to qualitative process research, given the

limitations created by restricted budgets and funding allocations (J. Lebow, personal communication, March 31, 2011).

Family Systems Nursing scholars have suggested that what is most needed in addressing the suffering that families experience in the presence of illness is family intervention research which has as its focus, an actual examination of clinical practice, an exploration of the illness conversations that nurses enter into with family members (Bell & Wright, 2007; Wright & Bell, 1994). Within the context of the Family Nursing Unit (FNU), where clinical practice has been guided by the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996), there has been an evolving program of qualitative process research which has focused on those interventional practices which aim to reduce, diminish, or alleviate family suffering in the context of illness. This research program has begun the process of better understanding what aspects of these intentional and purposeful conversations between families and nurses have the potential to invite healing in the midst of illness (Bell, 2008; Bell & Wright, 2007; Wright, 2005; Wright & Bell, 2009).

The Program of Process Research Evolving From the Family Nursing Unit

Carole Robinson was one of the first doctoral students to explore family systems nursing intervention based on clinical work emerging from the FNU (Robinson, 1994, 1998; Robinson & Wright, 1995) using a qualitative research approach. Robinson (1994, 1998) employed grounded theory methodology to explore the process and outcome of change that emerged as families living with chronic illness entered into therapeutic nursing conversations based on the IBM (Wright & Bell, 2009; Wright et al., 1996). This research revealed that the very act of bringing the family together to have a conversation

about their experience of living with illness, as well as the creation of a relational atmosphere of safety, comfort and trust, were key nursing interventional acts.

Tapp (1997, 2001, 2004) explored therapeutic conversations between nurses in the FNU and families living with cardiac illness. Her research revealed that there are many ways in which family members feel constrained from sharing conversations with one another about their experience of living with serious illness. When nurses invited families into therapeutic and purposeful conversations about their suffering, family members were able to share worries, conflicts and experiences of nagging; all of these influenced the nature of the conversations families shared about illness. As families entered into therapeutic nursing conversations, space was created to share concerns about the uncertainty of the future and fears about the possibility of death (Tapp, 2001).

Specific family intervention practices from the Illness Beliefs Model (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996) have also been studied by Family Systems Nursing researchers, including therapeutic letter writing (Bell, Moules, & Wright, 2009; Moules, 2000, 2002b, 2003, 2009a, 2009b), the offering of commendations (Houger Limacher, 2003, 2008; Houger Limacher & Wright, 2003, 2006), conversations of spirituality (McLeod, 2003; McLeod & Wright, 2001, 2008) and conversations about loss and grief (Moules, 2009c; Moules, Simonson, Prins, Angus, & Bell, 2004; Thirsk, 2009). Case study design has been used to examine the effectiveness of interventions offered in the FNU (Levac, McLean, Wright, & Bell, 1998; Moules, 1998; Moules, Thirsk, & Bell, 2006; Watson, Bell, & Wright, 1992; Wright, Bell, & Rock, 1989). Beyond these research studies, there have also been numerous publications which have described the clinical interventions that have been offered in the FNU (Bell,

Moules, Simonson, & Fraser, 2004; Bohn, Wright, & Moules, 2003; Levac, McLean, Wright, & Bell, 1998; Levac, McLean, Wright, & Bell, 1998; Marshall, Bell, & Moules, 2010;Moules, 1998; Moules, Thirsk, & Bell, 2006; Robinson, Wright, & Watson, 1994; Watson & Bell, 1990; Watson & Lee, 1993; Watson & Nanchoff-Glat, 1990; Wright, 1990; Wright & Bell, 2009; Wright, Bell, Watson, & Tapp, 1995; Wright & Park-Dorsay, 1989; Wright & Simpson, 1991; Wright et al., 1996).

One of the limitations of this program of research is the unique practice context from which it has emerged, the FNU. Nurses working in other clinical settings have needed to decide themselves how the practices described might be applied to their own unique clinical practices with family members. Further, within health care today, their has been only a slowly growing movement towards adopting the shift that is needed to move from individually focused care to health care provision that intentionally addresses the illness suffering of the entire family (Bell & Wright, 2007). Although these practice models have been taught widely in nursing education across North America and internationally, nurses working with families in present day acute/community care clinical settings continue to face significant knowledge translation challenges posed by the structure of their clinical work environments. Another limitation is that the clinical research which has emerged from the FNU prior to this has largely focused on adult populations. Carole Robinson's research on families living with chronic illness did include three families in which the ill family member was a child, but no research study emerging from this context prior to this has specifically explored therapeutic illness conversations with family members within a pediatric illness population. Additionally, the family members who have participated in the clinical practice at the FNU, case study

descriptions of that clinical work, and qualitative research studies, have been predominantly Caucasian, with middle-class socioeconomic backgrounds. Finally, the families who chose to come to the FNU and participate in the clinical interventions described may have been particularly open or ready to engage in family clinical intervention aimed at lessening their experiences of illness suffering.

Within this PhD dissertation research, I have conducted further family intervention research within the specific nursing context of the FNU and the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996). I have explored illness suffering in the context of childhood cancer, as well as the process of change as families and children who were suffering in living with childhood cancer entered into therapeutic illness conversations with nurses based on the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996). The FNU, a unique practice, education, and research unit offered an extraordinary opportunity for me to witness, explore, and interpretively analyze the interventional practices shared between nurses and family members who were suffering in the context of living with childhood cancer.

This research extends our understanding of illness suffering in the context of childhood cancer, and also explores how nurses and other health care professionals might intervene with ill children and families who are suffering in the midst of living with cancer, through the exploration and challenging of illness beliefs. It offers new understanding about how to speak with families about their suffering, how to challenge the beliefs that are sustaining their suffering, and how also to assist family members in sharing conversations about illness with one another. This is pioneering research, as no

other nursing researcher has employed family process research to explore actual clinical intervention with families suffering in the context of living with childhood cancer.

The research articulated within this PhD thesis could also be conceptualized as an enhancement or extension of the research conducted by Kazak and her colleagues. This research explored a family level intervention grounded in a Family Systems Nursing theoretical framework, but instead of examining outcome measures quantitatively, it employed process and qualitative research methodology to explore the how, the very process of change. This research facilitates an exploration of the internal dimensions of family level intervention in childhood cancer, rather than examining the beginning and endpoints of clinical intervention. As such, it provides new and important insights about how health care professionals may intervene with the aim of engaging and lessening illness suffering with families living with childhood cancer.

Concluding Thoughts: Significance of the Proposed Research Study

In qualitative research, children and adolescents living with cancer have described the various aspects of their illness suffering. They struggle to find a new sense of normalcy following the diagnosis of cancer (Björk et al., 2005; Clarke-Steffen, 1990, 1993, 1997; Earle et al., 2006; Haase & Rostad, 1994; Kars et al., 2008; Nicholas et al., 2009; Patterson et al., 2004; Rechner, 1990; Woodgate, 2000, 2006a), and experience suffering in relation to the isolation that accompanies this illness experience (Bearison, 1991; Enskär, Carlsson, Golsäter, & Hamrin, et al., 1997; Hockenberry-Eaton & Minick, 1994; Huang et al., 2008; Kelly & Ganong, 2011; Nicholas et al., 2009; Moody et al., 2006; Williams et al., 2009). Children have equated the very experience of cancer with pain (Fowler-Kerry, 1990; Enskär, Carlsson, Golsäter, & Hamrin, et al., 1997) and

suffering (Woodgate & Degner, 2003a). Also reported is the need for health professionals to understand their physical distress in the context of the meanings and beliefs that they assign to symptoms (Woodgate & Degner 2003a; Woodgate et al., 2003). Critical to the work of health care professionals in the future is the ability to better communicate with children regarding the beliefs they hold about their suffering (Woodgate & Degner, 2003a).

Children and adolescents draw great strength from their families (Aamodt et al., 1984; Bearison, 1991; Cantrell & Matula, 2009; Enskär, Carlsson, Golsäter, & Hamrin, 1997; Enskär, Carlsson, Golsäter, & Hamrin, et al., 1997; Haase & Rostad, 1994; Hockenberry-Eaton & Minick, 1994). Yet, families of children with cancer have reported living with an unspeakable sadness (Woodgate, 2003, p. 142, 143), as well as deterioration in family dynamics and family roles (Barrera, Chung, Greenberg, & Fleming, 2002; Chesler et al., 1991; Clarke-Steffen, 1990, 1993, 1997; Kelly & Ganong, 2011; Sloper, 2000a). Further, families report continued difficulty in speaking with one another and health care professionals about cancer, as well as the accompanying fears and sadness they carry as a part of this illness experience (Dixon-Woods, Findlay, Young, Cox, & Heney, 2001; Woodgate, 2003; Woodgate & Degner, 2003a; Yin & Twin, 2004; Young, Dixon-Woods, Findlay, et al., 2002; Young, Dixon-Woods, Windridge, & Heney, 2003).

Psychosocial clinical intervention for these families is considered a critical component of comprehensive care in childhood cancer (American Academy of Pediatrics, 2004). Yet intervention research at the family level has only recently begun to emerge in this population (Kazak, 1997, 2004; Kazak et al., 1999, 2004; 2007, 2009;

Kazak et al., 2005b). An evolving qualitative process-orientated research program has focused on studying advanced nursing practice guided by the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996). Nurses have conducted qualitative research and published case studies on therapeutic illness conversations with families suffering in the context of chronic illness (Bell, Moules, Simonson, & Fraser, 2004; Robinson, 1994, 1998; Robinson & Wright, 1995; Wright, 1997; Wright & Bell, 2009; Wright et al., 1996) and cardiac disease (Bohn, Wright, & Moules, 2003; Tapp, 1997; 2001; 2004), therapeutic conversations about spirituality (McLeod, 2003; McLeod & Wright, 2001, 2008), and the interventional practices of therapeutic letter writing (Bell, Moules, & Wright, 2009; Moules, 2000, 2002b, 2003, 2009a, 2009b), and commendations (Bohn, Wright, & Moules, 2003; Houger Limacher, 2003, 2008; Houger Limacher & Wright, 2003, 2006). The research from this qualitative hermeneutic exploration of how family intervention guided by the IBM (Wright & Bell, 2009; Wright et al., 1996) lessened the illness suffering of children and families living with cancer further extends knowledge within this research program, opening new for possibilities about how it may be applicable and helpful for children and families in the specific context of childhood cancer.

CHAPTER FOUR: SITUATING THE INQUIRY

Philosophical Stance

The Research Approach: Philosophical Hermeneutics

This research study was guided by philosophical hermeneutics, and informed by the philosophy articulated by Hans-Georg Gadamer (1989). It is important to be clear that Gadamer has not articulated a 'method' for qualitative research in nursing, but rather, has provided a careful and thoughtful articulation of a philosophy of hermeneutics, a philosophy which may guide researchers in the process of qualitative interpretation (Binding & Tapp, 2008; Jardine, 2006, 2008; Koch, 1998; Moules, 2002a; Schwandt, 1999). Gadamer (1989) suggested that "understanding begins….when something addresses us" (p. 299). This occasion, or event of an address arises "between" a "new eruption of life" (Jardine, 2006, p. 273) and what lies in the past, waiting to be interpreted in a new manner. Here there is an opening up to new possibilities, which may then lead to an expansion of understanding beyond what is known at the moment of an address. We are claimed by the topic, invited into a new dialogue with the topic. Jardine (2006, p. 273) suggested that:

> Hermeneutics requires that we attempt to experience this happenstance incident as so to speak, "speaking to us," having something to say to us beyond what we might be able, as yet, to say of it… "Rather than meeting us in our world, it is much more a world into which we ourselves are drawn. (Gadamer, 1994, p. 191, 192)

The aim of hermeneutic interpretive research, of responding to the address of illness suffering in the context of childhood cancer, is to better understand how this topic

is at play in the world. Within the hermeneutic research tradition, understanding is characterized not only by a grasping, hearing, or catching of meaning, but hermeneutic interpretation asks the researcher to participate in the actual creation of meaning (Smith, 1994). Herein we find one of the aspects of the hermeneutic research tradition that distinguishes it from other qualitative research traditions.

The Historicity of Hermeneutic Interpretation

A central characteristic of hermeneutic interpretation lies in its historicity, the tradition we are, the history that comes as context for an emerging creation of meaning. Gadamer (1989) argued for our belonging to human history, for the emergence of the past, for a living of the past, deep within the present. History needs to be accounted for, the researcher is asked to move to a different place of acknowledgement and responsibility to history. Gadamer (1989) has articulated how understanding emerges in the presence of the prejudices the researcher brings to consideration of the topic. He argued that the history we are, the prejudices that bring us to the path of hermeneutic interpretation, are not a troublesome aspect of inquiry, but rather, needed in the process. The prejudices we bring are in part what allows the research text to say something to us; they are an opening into dialogue, into an exploration of the research topic and questions. The researcher must, however, responsibly account for the prejudices they bring to the process of interpretation.

Part of the responsibility in accounting for our prejudices involves the crafting of a deepened sensitivity to those prejudices that are hidden from view, those that lie outside of our present awareness. The researcher commits to an ongoing search, to an unending effort throughout the research process to illuminate his/her prejudices, so that they may

enter the research dialogue, allowing a deepened and more responsible understanding and accounting of the topic. It is in the constant process of entering a dialogue with the other, a dialogue with ourselves, and a dialogue with the text, that there is an opening of our own position and beliefs, an opening to the other (Binding & Tapp, 2008), to that which is different from what we know. New possibilities for understanding are then opened, as we hear what the other has to say (Gadamer, 1989) about the topic that lies between us.

The Dialogical Nature of Hermeneutic Interpretation

The act of entering into the interpretation involves an engagement with one another and the topic in genuine dialogue (Binding & Tapp, 2008), which is accompanied by the fostering of a sensitivity and curiosity about language, attentiveness to the living history that words hold. The dialogical nature of the interpretive process is also reflected in the relationship that emerges between the topic as it lives in the world and the instances studied within the research process. Each speaks to the other, engaging and expanding the understanding of the play that was in process prior to falling into this new and generative dialogue.

The relationship between the topic and the 'instance' is interpretive in nature, the new instance transforms and re-creates what the topic is in the world, and in turn the topic "helps articulate what the instance means" (Jardine, 1992, p. 56). In this research approach, the researcher acknowledges the deep interconnectedness found in the world (Smith, 1994), object and subject, topic and instance, live, exist, and learn from one another in a connected, reciprocal, and relational manner. This brings a challenge to the pervasive belief that object and subject exist as separate entities: "a clear split between

subjective and objective thinking is not sustainable because my subjectivity gets its

bearings from the very world I take as my object" (Smith, 1994, p. 108).

Reading Stories from the Inside Out: Finding a Dialogical Path into the Topic

Hermeneutics asks the researcher to acknowledge and enter the storied existence

of their lives and that of the participants. Dwelling with the particular nature, the

uniqueness of this story may open the door; provide a path to a better understanding of

how this topic lives in the world. It is essential to remember the circularity between part

and whole: an embrace of the particular demands also an embrace of the whole,

> the relationships between the instance and that to which it seems to bear a 'family
>
> resemblance' is always in a type of suspense. Interpretive inquiry in the context of
>
> hermeneutic philosophy, does not wish literally and univocally to say what this
>
> instance *is*. Rather, it wishes to playfully explore what understandings and
>
> meanings this instance makes *possible*. (Jardine, 1992, p. 56)

This suspense between the instance and the topic also can be found reflected in

the linguistic nature of hermeneutic interpretation. There is an acknowledgement that

each word comes with a history; it stands in relation to the world of which it is a part.

The hermeneutic researcher strives to attend to the world that is brought forward through

an engagement with the words of the research text. In speaking of the dialogical nature of

language, Gadamer (1989) argued that every word needs to be accorded an inner

dimension of multiplicity; each word has a character which embeds a history as well as

yet unrealized possibilities of understanding. Adopting a hermeneutic research approach,

requires the asking of the following questions: What is concealed in the spoken language

we share? How can we come to move deep beneath the surface of what is being said?

Concluding Thoughts: Philosophical Hermeneutics and Nursing Knowledge

Is nursing an interpretive practice and how appropriate is the fit between philosophical hermeneutics and nursing knowledge? There is an undeniable connection between hermeneutics and research questions which centre on illness suffering, and the practices of nurses. This is partly because the moments, events, or instances that address us, come from and through our experiences in practice. What allows this instance to make a claim on me, to call out to me, is the nursing practice I find myself embedded in. As we enter the process of hermeneutic interpretation, there is a

> shaping and making something of this instance and its human topographies…[but within hermeneutics there exists the recognition that I am also]…shaping and making something of myself in the midst of this world in which I work as a teacher, a writer, a scholar…[a nurse]. (Jardine, 2006, p. 281)

The cultivation of who I am, how I live with this topic, how I understand what it has to say, how I practice, are all interwoven and intimately connected with one another.

The word interpret is connected etymologically to the word explain, which in turn finds a relationship with the following phrases: to unfold, open out or assign a meaning to (Hoad, 2003). To unfold, open out, or to assign meaning to suffering, to engage questions about the illness suffering of families, is to enter not only the hidden, often concealed world of childhood cancer, but also the unspoken, confusing, and distressing corners of nursing practice. The practice of nursing and interpretation share the task of "learning to face, to love this odd, irremediable "invalidity" that is inscribed at the heart of human life" (Jardine, 2000, p. 198). I suggest that within childhood cancer there is nothing considered more invalid, troublesome, or dangerous than invoking the voice of suffering

and the silence it often invites into relationships, those shared by family members and those shared by families and professionals. In a similar echo, Arthur Frank (2001) suggested there are some aspects of suffering that remain "unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal; it remains in darkness eluding illumination; and it is dread, beyond what is tangible even if hurtful" (p. 355). If we make a choice not to engage the voice of suffering, what do we risk, what may be lost? When we are unable to engage the suffering of the other, do we fail to come face to face with one of the essential tasks of nursing practice, of human life?

In this writing, I come with an evolving assumption that something essential is lost, that there is an enhancement of suffering because of the silence, because of our disengagement from the questions that suffering may be posing. Yet to enter this wondering in a hermeneutic manner, I must also consider, remain open to the possibility that I might very well be wrong in this assumption, or at least be coming with an incomplete understanding, only a piece of 'truth.' What will be most important, is the choice and commitment to remain open, "not thinking something is known, for when we think we already know, we stop paying attention to what comes to meet us" (Moules, 2002a, p. 23). Truth rather than stagnant is described by Gadamer as the event of meaning, living, changing, expansive and full of possibilities: "the truth is what allows the conversation to go on, recognizing that understanding is not a solo undertaking for it always occurs with others" (Moules, 2002a, p. 23).

Within the next chapter, I will explore the research process that I embarked on within this dissertation, focusing on data generation, recruitment of participants, ethical considerations, and the process of analysis and interpretation.

CHAPTER FIVE: THE RESEARCH PROCESS – A CONTINUAL MOVEMENT

BETWEEN DATA GENERATION, ANALYSIS, AND INTERPRETATION

Clinical Research Context: The Family Nursing Unit

The context for this family intervention study was the Family Nursing Unit

(FNU), at the Faculty of Nursing, University of Calgary. The FNU, described earlier in

this thesis, was an educational, research, and clinical practice unit which assisted families

who were suffering in the midst of chronic, life-threatening, or psychosocial illness (Bell,

2008; Flowers, St. John, & Bell, 2008; Gottlieb, 2007; Wright & Bell, 2009; Wright et

al., 1990, 1996). The clinical work at the FNU was guided by the IBM (Bell & Wright,

2011; Wright & Bell, 2009; Wright et al., 1996), as well as the Calgary Family

Assessment and Intervention Models (Wright & Leahey, 2009) and the Trinity Model

(Wright, 2005). The aim and direction for family intervention was the alleviation of

illness suffering through purposeful therapeutic conversations in which the human

experiences of suffering in illness, as well as family experiences of courage, hope,

strength, growth, and love, were drawn forth (Wright & Bell, 2009; Wright et al., 1996).

The IBM is based in part on the knowledge that at the core of illness suffering lay

the beliefs that family members hold about illness. Certain beliefs, those called

constraining, may conserve or maintain illness suffering, while other beliefs, those that

are facilitating, may hold the possibility to alleviate or lessen the human suffering

experienced by family members in the context of illness. A belief is defined as: the

"truth" of a particular reality that influences a person's "bio-psychosocial-spiritual

structure and functioning" (Wright & Bell, 2009, p. 41). The distinguishing of those

beliefs that are constraining and those which are facilitating for family members is a

clinical judgment made by the nurse clinician and nursing team in careful collaboration

with family members. The same illness belief may be constraining for some families, but

facilitating for others. Further, there is attention paid to the intersection of three very

distinct sets of beliefs: "those of the ill patients, those of other family members, and those

of the health care providers" (Wright & Bell, 2009, p. 24). These in turn are embedded in

the beliefs of the larger society and/or culture in which the family and health care

professional lives. The therapeutic illness conversation has been described as the medium

for the offering of this advanced nursing practice: "a collaborative, strengths-focused

relationship that makes room for multiple realities" (Bell, 2008, p. 276). Both the family

and clinician are understood to bring their own expert knowledge and understanding to

the therapeutic conversation. As this shared expertise is acknowledged and honored,

family members and the clinician may experience changes or challenges to the beliefs

that they brought into the clinical encounter (Wright & Bell, 2009). The nurse

understands that she has as much to learn from family members as she does to offer them

in the way of interventional practice.

Within this practice model, the nurse works to distinguish the illness beliefs held

by family members. These include beliefs about illness suffering, diagnosis, etiology,

healing and treatment, beliefs about mastery, control, and influence, prognosis,

religion/spirituality, as well as the place of illness in lives and relationships (Wright &

Bell, 2009). When the illness beliefs are enhancing or sustaining the suffering of family

members, nurses work to challenge constraining illness beliefs by offering new

facilitative beliefs. Some of the interventions described in this practice model include:

"asking of interventive questions, speaking the unspeakable, offering alternative beliefs,

using research findings, offering externalizing conversations, writing therapeutic letter, offering commendations, and using reflecting teams" (Wright & Bell, 2009, p. 226). Within this approach to family intervention, therapeutic illness conversations help families to speak about their concerns, and the unique ways they are suffering in the context of living with illness.

The Family Intervention Practice

Families are seen by a clinical nursing team for an average of four to six clinical sessions, over a period of three to six months. The frequency and timing of all clinical sessions is determined by family members. Families who participated in clinical work as a part of this research study were seen by either a faculty member of the FNU who brought expert knowledge in Family Systems Nursing, or by a graduate nursing student who was supervised by a faculty member. Each clinical session was videotaped once the family and nurse clinician had given written consent. The families participated in clinical work with a nursing team that included faculty members and graduate students. The clinical work that was offered to families at the FNU was modeled after the five-part session previously described by the Milan family therapy team (Selvini Palazzoli, Boscolo, Cecchin, & Prata, 1980; Tomm, 1984a, 1984b). All of the above is standard practice for any families who participated in clinical work at the FNU.

The Recruitment of Research Participants

The selection of participants was done by purposeful sampling (Coyne, 1997; Morse, 1986, 1989; Patton, 1990; Sandelowski, 1995). In hermeneutic interpretation, there is value placed on the depth of understanding that becomes possible with a detailed and layered interpretation from a small number of research participants. A total of three

families were recruited. The participants for this research study included children with cancer, their healthy siblings, and parent(s), as well as the nurse clinician(s) who were involved in the clinical work. In chapter six, I will provide a brief introduction to the families who consented to participate in this research study.

Families Who Participated in Family Intervention at the FNU

Parent(s), children with cancer, and siblings who had received assistance at the FNU and met the inclusion criteria (see appendix A) were asked to participate in this research study. I had planned to send the parent(s) from each potential research family an information letter in the mail to explain the research study. However, given that each of the families who participated in this research had attended clinical sessions at least four years prior to the time we planned to approach them for research participation, either my supervisor, Dr. Janice Bell, or Dr. Nancy Moules, who is a member of my PhD supervisory committee, contacted each family by phone to inquire about whether they might be willing to participate as research participants. If parent(s) indicated an interest in participation, I contacted them to answer any further questions, as well as to discuss the parent's willingness to have their children participate in the research. I explained to the parent(s) that even if they gave permission for their children to participate, the children themselves needed to agree, and would be asked to give written assent for research participation.

I then arranged to meet with the parent(s) or family group at a time and place of their choice to further discuss and obtain written consent for research participation. The written consent for parental participation can be found in Appendix B. Once the parent(s) had consented to research participation for themselves and their children, I met with the

children to explain the research study in language that the children could understand, and obtained their written assent. The written assent form for brothers and sisters who participated in this research can be found in Appendix C. The inclusion of family members who had previously received clinical work at the FNU was beneficial as they had had time to reflect upon how participation in this clinical intervention may or may not have been helpful for them as individuals and a family.

Nurse Clinicians Who Participated in the Family Intervention

Nurse clinicians who had participated in the family clinical intervention at the FNU were also asked to participate in this research study. Each of these nurse clinicians had participated in the therapeutic conversation in the context of a larger nursing team, and each had been given live supervision by an expert Family Systems Nursing faculty member who sat with the rest of the nursing team behind a one way mirror within the FNU interviewing suite (Bell, 2008). Nurse clinicians were contacted in a similar manner to that described for the family participants. Once the nurse clinician(s) indicated an interest in research participation, I contacted them to answer any further questions, and arranged to meet with them at a time and place of their choice to obtain written consent for research participation (see Appendix D). All nurse clinician(s) who had participated in the clinical intervention with the research families agreed to participate in research interview(s).

<div align="center">

Ethical Considerations

</div>

The ethical accounting within this hermeneutic interpretation was addressed throughout the duration of the research process. It held a focus on process rather than being seen as a one-time event of comparing predicted benefits and risks of participation

(Cohen, 2000; Cohen & Morse, 2003; Cutliffe & Ramcharan, 2002; Ramcharan & Cutliffe, 2001). Consent was established in an ongoing manner and then periodically reestablished; participants were reminded regularly that they could withdraw from the study at anytime and were reassured that if there were questions they would rather not answer they could ask the researcher to move to the next question. The researcher worked to ensure that participants did not feel pressured or coerced into continuing at any point (Knox, Mok, & Parmenter, 2000) and watched carefully for situations in which research participation might have become intrusive for participants (Stalker, 1998).

Of great importance throughout the research process was the creation of sensitivity and attentiveness to the emotional and psychological distress that might possibly emerge as participants entered into research interactions. Within an ethics as process approach, the researcher's engagement with participants involves a commitment to establishing and sustaining trust throughout the project (Corbin & Morse, 2003; Ramcharan & Cutliffe, 2001).

The attention to relationship within the research process also required a careful accounting of how the researcher concluded with participants (Corbin & Morse, 2003; Ramcharan & Cutliffe, 2001). At the completion of the research interviews, family members were told that they could contact the researcher at any time to speak further about the research, their family experience of living with childhood cancer, or their experience of having participated in therapeutic nursing conversations at the FNU. Family members were asked if they would like a copy of the final research report/dissertation as part of their participation in the research. Every family who participated in this research indicated an interest in receiving a copy of the final

dissertation. I will contact them to provide a copy of my dissertation following the final

oral defense of this research. This activity will not occur for the purpose of "member

checks" (Acker, Barry, & Esseveld, 1983; Cutliffe & McKenna, 1999), but to allow

participants ongoing involvement in the study, as well as opening the possibility for a

continuing enrichment of the hermeneutic interpretation.

Another aspect of attending to the emotional and psychological well being of

participants was the creation of a 'safety net' for participants (Corbin & Morse, 2003): if

emotional distress had emerged within the course of the research, participants would have

been offered counseling support from a social worker previously known to the family

from the Hematology/Oncology Program or alternatively the clinical nursing team at the

FNU, Faculty of Nursing, University of Calgary. No family member indicated the need

for counseling support following participation in the research interview(s), and in fact,

two parents who participated reflected upon how the process of participating in the

research interview had improved interactions and connection with the children who had

shared some of the research interviews with them.

Privacy, Confidentiality, and Anonymity within the Research Process

Every attempt was made to ensure the confidentiality, privacy and anonymity of

the research participants was maintained. The names of participants were replaced with

pretend names/pseudonyms; these were used to replace the actual names of participants

in the transcripts of interviews as well as in any final research reports. All participants,

whether adult or child, were informed of these measures, and were given the opportunity

to help choose the pretend names. During the time of this study, all of the data was stored

in a locked cupboard or on a computer protected by a password known only to the

researcher. The only people who had access to the data were Christina West (the doctoral student), her supervisor (Janice Bell, RN, PhD) and members of the supervisory committee (Nancy Moules, RN, PhD, Roberta Woodgate, RN, PhD). The researcher was also sensitive to the need that children, family members, and nurse clinicians had for privacy and confidentiality during data generation. They were given a choice about the location of the research interviews, and privacy was ensured throughout the research interviews. Consistent with the ethics as process approach, participants were given continual and ongoing assurance that the information they shared with the researcher would be kept confidential and private (Faux, Walsh, & Deatrick, 1988).

<div align="center">**Sources of Research Data**</div>

Videotapes and Written Documentation of Clinical Sessions

It is standard practice at the FNU to obtain parent consent, child assent, as well as nurse clinician consent for the videotaping of all clinical sessions prior to beginning any clinical work. All clinical sessions are videotaped within this practice setting, with family members given the following options within the consent process: use of videotapes for graduate student education, professional presentation or publication of clinical work, and/or FNU research. In addition to the standard consent for the videotaping of clinical work, all research participants were asked to consent to the use of the videotapes of clinical sessions as an additional source of data (see consent forms in appendix B, C, D). Research participants were also asked to consent to the use of the written documentation of clinical intervention sessions as an additional source of research data.

Research Interviews

As Gadamer (1989) has not articulated a method for human science research, but rather a philosophy of hermeneutics, it is essential that all aspects of the research endeavor be informed by that philosophy; the philosophy guides not only the generation of an interpretation but also the very process of generating data (Crist & Tanner, 2003; Geanellos, 1999; Wimpenny & Gass, 2000). This research approach, therefore included research interviews that resisted tight structure and prescriptive questions prepared prior to the interview (Kahn, 2000). Guiding questions/probes (Appendices E, F, G) were helpful in the research interview, but the researcher was careful not to allow the questions to become directive in nature, structuring the interview in a predetermined way (Kahn, 2000).

Questioning holds the aim of creating openness to new understandings and meanings: "the essence of the question is to open up possibilities and keep them open" (Gadamer, 1989, p. 299). It is in the open and questioning nature of the hermeneutic research interview that the possibility is created to break open the research topic. The dialectic between question and answer is central to not only the research interview, but also to generation of a hermeneutic interpretation. The research interview is part of an unfolding process of learning and understanding that leads to the generation of an interpretation. Understanding, interpretation, question, and answer come to be inseparable within this research approach. Guiding questions were prepared for the research interviews, but there was flexibility in how they were used, which depended on the unfolding of each research interview and the leading of the topic.

Parents/legal guardian(s), ill children, and siblings who met the inclusion criteria and agreed to be a part of this research were asked to participate in at least one research interview, with the option of a second interview. Woodgate (2000) suggested that multiple interviews can be helpful in developing rich and detailed qualitative findings, as well as in building trust between adult researchers and child participants. For each of the families who participated in this research, there was more than one research interview done. Further, each research interview was between two and three hours in length. It was made clear to all of the research participants that if at any time they became fatigued, we could stop the interview, take a break and then restart, or have a second interview at a later date. Research participants were also made aware that they could choose to end their participation at any time during the research process. All of the research interviews were tape recorded and later transcribed by myself. Family members were given a choice about whether they wanted to participate in the research interviews together or separately.

Field Notes

I wrote field notes throughout the research process, in order to create a textual account of my observations of the physical environments in which the interviews took place (Kahn, 2000), and to account for reflections or observations that occurred throughout the research process. These notes included recordings about vocal intonations, moments of conversation silence, body language, distractions, gestures, and emotions emerging in the research field. Field notes were written as soon as possible following each research interaction (Crist & Tanner, 2003).

Understanding the Research Process as a Circular Movement

In philosophical hermeneutics, a move into the data analysis phase of research is not conceptualized as a separate, isolated activity but rather as an extension of the interpretive process, a process that began with the address of the topic, and the accounting for the prejudices brought to the research. There is a movement back and forth between the dialogical engagement of researcher and participant to that of researcher with the text. This circular, playful, recursive movement between the part and whole has been described as the hermeneutic circle (Heidegger, 1996). It is this fluid movement between the part and whole, the particular and the universal, the word and the sentence, the research interview and the transcripts of videotaped clinical sessions, the research texts and broad sources of literature, which characterizes the act of interpretation.

Prior to the research interviews, all of the videotapes of the clinical sessions were reviewed in depth, first for reflections about the whole of the work. The first review involved a viewing of the videotaped clinical work from the beginning to end of the clinical intervention with each family. The researcher then chose particular videotaped segments of the clinical work which reflected family-nurse interactions in which the illness suffering of family members was addressed. Any videotaped sections which included therapeutic conversation segments that addressed the questions that family members asked themselves as part of their illness experience, or illness beliefs they held that enhanced or sustained their experience of suffering, were also included.

Videotaped segments which were identified as central to the process of change, including those segments which led to a change in the experience of illness suffering

(Wright & Bell, 1994) were selected for transcription. Within each videotaped segment, I carefully attended to how the nurse clinician responded to the family, and how the family responded to the nurse (verbal and non-verbal interaction). Each of the videotaped segments selected for possible viewing within a research interview was then transcribed (Wright & Bell, 1994). This process involved the viewing of many hours of videotaped clinical sessions (total number of videotaped hours reviewed = 57 hrs). If a particular aspect of clinical work at the FNU was referred to or discussed within the research interviews with the families or nurse clinicians, I returned to the clinical videotapes, for further clarification and interpretation (see Figure 1). Not all of the videotaped segments chosen were shown within the research interviews. The selection of videotaped segments reflected my impressions and interpretations of what was helpful or significant to the families within the process of clinical intervention. At times, I entered the conversations and found that family members did not find the selected segments to be significant for them. However, the majority of the videotaped segments chosen for review were viewed within the research interviews.
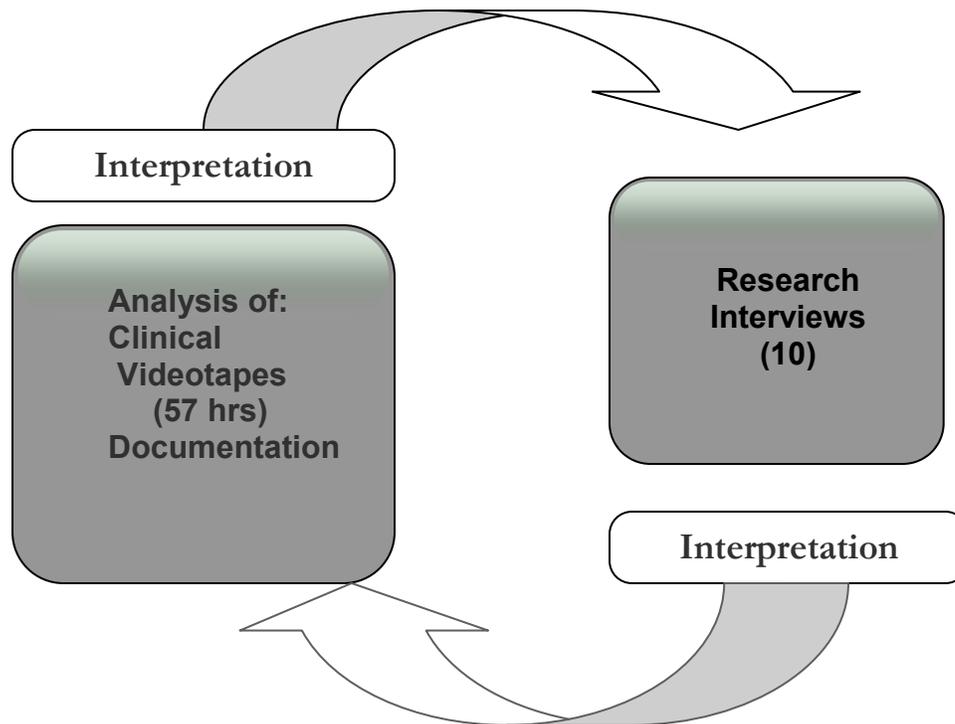
Figure 1. The Process of Analysis and Interpretation

For further clarification about the research analysis and interpretation, I will provide one example of how the process of inquiry occurred. During the initial review of the videotaped clinical work with the first research family, I observed a significant change in a potentially core constraining illness belief for Jan (parent) between the first and fifth clinical session (see chapter nine for the interpretation related to this therapeutic change). Jan initially believed that her role as a parent was to protect her children from the struggles and hardships of life. Within the fifth clinical session, Jan shared a dramatic change in her previously held illness belief: rather than protecting her children from pain and difficulty, she had come to believe that she needed to teach her children that difficulties would come to them in life, and it is in facing those difficulties that they could develop character, endurance, and even compassion. Jan's initial struggle with her

inability to protect her children from harm had not been specifically addressed within the therapeutic conversation with the nurse clinician, so I became very curious about how this dramatic change in her belief had occurred.

Within one of our research interviews, I explored these specific videotaped segments with Jan and Ben (father), and Jan shared that what had been helpful to her in coming to this new illness belief was the nursing team's ability to provide the family with new perspectives about their situation. After the research interview, given Jan's reflections, I returned to the clinical videotapes and discovered a clinical segment within the first clinical session (nursing reflecting team) where the nurses had offered their thoughts on how difficult it must have been for Jan and Ben as parents to learn that they could not protect their children from this illness experience, and then the nurses questioned whether there may be some wisdom embedded in the horribleness of their experience. Had this illness experience taught these parents something important about how they might learn to navigate the difficulties that they and their children would encounter in life?

What is important here is the circular movement that occurred in the research inquiry between the analysis of the clinical videotapes, and the research interviews with the family members and nurses. There was a movement back and forth between these research data sources (see Figure 1) which allowed an ongoing deepening and enhancement of the meaning within the hermeneutic interpretation. During the initial viewing of the clinical videotapes, the alternative beliefs offered in the first clinical session (nursing reflecting team) had not stood out, but in bringing the initial interpretations from the analysis of the clinical videotapes to the research interviews, new

meanings were encountered within the research dialogue with the family members and nurses, which often led to a subsequent return to the clinical videotapes. To assist the reader with their reading and understanding of the interpretation, transcribed segments from the clinical videotapes are **not** italicized, while the transcribed segments from the research interviews do appear in italics.

The Fusion of Horizons

In articulating a philosophy of hermeneutics, Gadamer (1989) chose the metaphor of a fusion of horizons to explain how understanding occurs. The researcher enters the interview with a beginning understanding of the topic; this initial horizon of understanding consists of all the researchers' prejudices, those in awareness and those hidden from view. It is here within this initial horizon, and in the accounting for our prejudices, that understanding begins. What needs to be grasped is that in moving towards a fusing of horizons there is an ongoing, evolving and creative process of testing the prejudices brought to the act of understanding. An integral aspect of this testing is exploring tradition, the history from which we come and the past that lives with us here in the present.

Understanding always involves a fusion of this initial horizon with the horizon opened up through the process of interpretation. The present horizon of prejudices is drawn into dialogue, opened out into an engagement and dialogue with the text. The research interview requires an embracing of the hermeneutic task, the aim of which is not to cover up but draw out the tension that exists between the researchers' prejudices and the understandings which emerge with the generation of an interpretation. It is in this dialogical engagement where meaning is created: "to acquire a horizon means that one

learns to look beyond what is close at hand – not in order to look away from it but to see it better, within a larger whole and in truer proportion" (Gadamer, 1989, p. 305).

The Practice of Hermeneutic Writing: Generating an Interpretation

Hermeneutic writing is a research practice, the place in which the researcher dwells with the text, turning it over and over again. It is in the interpretive act of writing that generative meaning is created. "Writing is a process of discovery" and the "researcher's self-knowledge and knowledge of the topic develop through writing" (Richardson, 2000, p. 936). In the practice of writing, the researcher discovers new ways of engaging the topic, the text created by the research conversation, the stories of research participants and the very world in which we live. "The writer dwells in the space that the words open up," (van Manen, 2002, p. 2); this is a world of light, but also a world of shadows and darkness. It is in this place that "one develops a special relation to language, a reflective relation which disturbs its taken-for-grantedness" (pp. 3-4). Hermeneutic interpretive writing, in many ways, is an invitation to an ongoing conversation, for the act of interpretation is a process that necessitates a living into the future; it awaits new unfoldings, openings, and understandings. The need to remain open is of the utmost importance, for there is always the possibility of coming upon a new, engaging instance that will break through, break down, or break open our understanding, addressing us in ways that we could have never imagined. Throughout the research process, I wrote interpretive memos which opened up different aspects of the hermeneutic interpretation. These memos were written during the analysis of videotaped segments, following research interviews, following conversations with hermeneutic research colleagues, as

well as in response to personal and clinical practice experiences that occurred during the process of interpretation.

Hermeneutic Interpretation: A Research Approach That Opens Up Generative Learning

A hermeneutic research approach does not hold an aim of generalizing findings to large populations through statistically representative population samples. In hermeneutics, understanding that emerges from the instance makes possible the interpretive dialogue which leads to the creation of a new view of the topic. At first glance, it may be appear that this approach adopts a focus on the particular, but the universal remains a present and enduring feature of philosophical hermeneutics. What is asked of the researcher, and of the writing, is an articulation of what is at play in the "tension between particularity and universality" (van Manen, 1990, p. 120). The instance, this particularity, says and asks something of the researcher in the reading. Through questioning, the researcher is led to new and generative understanding about how the topic lives and breathes in the world. The subjective always stands in relation with the world, longing to speak about the topic; yet even as the instance finds itself in the universal, it remains in a conversational relation with the particularity it brings to understanding (Gadamer, 1989; Jardine, 1992; Smith, 1994). The instance itself is transformed by the topic within the act of interpretation, while the topic also faces a transformation, a creative evolution of how it lives in the world, in other instances, populations, and clinical settings.

In a discussion of the use of qualitative findings, Sandelowski (2004) suggested that, as researchers and authors, there is a need to better understand and promote the symbolic and conceptual utilization of qualitative findings. Understanding is not merely a

prelude to action, but is in itself action, or consequence to action. In the seeing, in understanding differently, change is invoked in the world and change is invoked in practice: "whenever users see something for the first time or see it differently, they change the world" (Sandelowski, 2004, p. 1373). The stories themselves, stories of the particular instance, act to do much more than evoke emotion, or tap into subjective experience. The stories and interpretations that emerge in the research endeavor, invite change and action "because they invite listeners/readers to use them to tell new stories" (p. 1373); within the reading there lies transformative possibility.

Rigor: Accounting for a Good Hermeneutic Interpretation

In reading a good hermeneutic interpretation, there is a sense of recognition, a sense of not only knowing the people whose words are encountered on the page, but also in the reading there is a greater recognition of the self. The interpretation also needs to show a responsibility for the contextuality it possesses (Madison, 1988). As well, there is a need for suggestiveness and potential within the interpretation. A good interpretation is thought to be one holding the character of fertility. New questions need to be raised, which in turn lead to successive interpretations and further explorations in research. The ultimate validation of a hermeneutic interpretation is thought to lie not in a present day judgment, but instead it will be found in the future.

Gadamer guided the hermeneutic research community to understand the central place of application: "the text…if it is to be understood properly – i.e., according to the claim it makes – must be understood at every moment, in every concrete situation, in a new and different way. Understanding here is always application" (Gadamer, 1989, p. 309). Hermeneutics is first and foremost a transformative practice. Truth is understood

not as something that can be grasped once and for all with certainty but as having a living character, changing with each new moment of understanding, within each contextual setting and with each new interpretation.

With the surrender of an adherence to strict methodology and highly specific criteria, interpretive researchers are called to foreground the moral and pragmatic concerns in evaluating the goodness, validity, and trustworthiness of interpretive research endeavors (Angen, 2000; Kvale, 1996; Unger, 1992). There is a moral responsibility to illustrate how the researcher's prejudices have been tested, challenged, and transformed within the process of inquiry. The researcher is obliged to ask the following question: "What do I now know or see that I did not expect or understand before I began reading the text?" (Benner, 1994, p. 101). There must be a showing in writing of how the prejudices brought into the research process have been extended, how the horizons of meaning have undergone a fusing. The path towards the creation of new and generative knowledge needs to be evident in the work.

Credibility and confirmability are two other criteria held out for establishing the trustworthiness of qualitative findings (Clayton & Thorne, 2000; Lincoln & Guba, 1985). Credibility is attained by ensuring that the perspectives of participants is represented as clearly as possible. Confirmability involves returning to participants throughout the research process to validate the findings of the research (Koch, 1994). However, Allen (1995) challenged the use of 'member checks' in research guided by a hermeneutic philosophy. The validation by research subjects does not hold the same epistemological or methodological primacy in hermeneutics. Rather than capturing or reproducing the original meaning of subjective responses, hermeneutic interpretation focuses on the

creation of new understanding. Meaning is understood as being intersubjective and not contained within either the researcher or participant. Within this research, I followed the alternative process suggested by Allen (1995): a review of the interpretation by other readers occurred multiple times within the research process. This facilitated a deepening of the writing in relation to intersubjective meaning, and facilitated the opening of the interpretation to the blindness it possessed.

Concluding Thoughts

This chapter has focused on the research setting, recruitment of research participants, data generation, as well as the process of hermeneutic analysis and interpretation. Within the next chapter, I will introduce the family members and nurse clinicians who participated in this research study.

CHAPTER SIX: AN INTRODUCTION TO THE FAMILIES AND NURSE

CLINICIANS

Within research guided by philosophical hermeneutics, there is an acknowledgement that it is not the particular research participants that stand at the centre of the inquiry, but rather the research topic. What is central to the inquiry is an exploration of the experience and knowledge that the participants have in relation to the research topic. Moules (2002a) described data generation within hermeneutic inquiry as a "gathering and harvesting of experience" (p. 29).

The family participants that were gathered or brought together for this research study represented three different families. In total, there were eighteen family members who participated in the clinical intervention at the FNU. Each of these family members had consented to the use of their clinical videotapes for the purposes of research, education, and publication. Of those eighteen family members, six completed research interviews (three mothers, one father, and two siblings). Below, I will provide a brief description of each family, including information on the duration, and timing of the clinical intervention that they participated in at the FNU. Following the introduction of each research family, I will introduce the nurse clinician who interviewed the family as part of the clinical intervention. It is important to remember that the nurse clinicians were supported by a nursing team which included a Family Nursing Unit faculty member who brought extensive theoretical and practice experience in Family Systems Nursing.

The First Research Family

The first research family attended the FNU for a total of six clinical sessions. The clinical work began in September 2004, and concluded following the fifth clinical session

in June of 2005. The family then returned for one follow-up session in February of 2006.

At the time of the clinical intervention, Cameron, the ill child, was 13 years old. He had

been diagnosed with an aggressive, abdominal tumor in January 2004 following a

hospitalization for the surgical removal of his appendix. At the time of the first clinical

session at the FNU, Cameron had recently completed intensive chemotherapy treatment.

Following the completion of Cameron's cancer treatment, Ben (father) developed clinical

depression, and at the time of the first clinical session, Ben was being treated by a

psychiatrist. It was the father's psychiatrist who referred the family to the FNU for

clinical intervention. At the time of the initial referral, the family reported feeling

overwhelmed by their situation, and posed the following question as part of the referral:

"How can we use the anger to deal with this?"

Ben (49 years), and Jan (48 years) had been married for many years, and came to

the FNU with multiple biological children. Cameron (13 years), the ill child, was the

third youngest child in the family. The children ranged in ages from 8 years to 24 years of

age. One of their young adult children did not live in the family home at the time of the

clinical intervention. The family was easily engaged within the context of clinical work,

and openly shared their family history. Although they described a close relationship with

their extended family, only one of Jan's siblings, a sister, lived in Calgary at the time of

Cameron's illness. This family member had a graduate degree in science, and both

parents reported calling upon her to assist them with research and the gathering of

information in relation to Cameron's illness and proposed treatment plan. Jan was

described by the family as "the rock," and their "patron saint." The family moved to

Calgary in the 1980s from a rural setting, and valued the keeping the family together as

much as possible. Jan had home schooled each of the children for part of their education, and spoke about their Christian faith as guiding the standards and values that she and Ben had raised the children upon. The values that marked their family life included building one another up, being kind, and caring for one another. As parents, they believed it was important to be open and honest as a family about Cameron's diagnosis and treatment.

The family unit, including the ill child, brothers, sisters (one sister was missing due to a scheduling conflict), and both parents attended the first two clinical sessions at the FNU, but following this, the clinical work became focused primarily on the marital subsystem. Four family members participated in research interviews for this doctoral dissertation: Ben (father), Jan (mother), Lizzie (10 years old at the time of clinical intervention, learning disability), and Jason (8 years old at the time of clinical intervention). The research interviews were conducted four years after this family participated in clinical intervention at the FNU.

Within the clinical practice at the FNU, near the end of the first clinical session, every family is asked the 'one question question' (Duhamel, Dupuis, & Wright, 2009; Wright, 1989): "If you could have just one question answered in our work together, what would that question be?" (Wright & Bell, 2009, p. 99). The rationale for asking this question is that it can invite "family members to focus on their deepest concerns or suffering" (Wright & Bell, 2009, p. 99). For this research family, there were multiple questions/responses that were offered to the nursing team for consideration: "Is there an end?" (Ben) "How do we cope with the loss of control?" (Jan) "When will I be able to sleep at night and feel comfortable making plans?" (Stephen) "How do you pick up the pieces?" (Kathy) "When can you stop worrying?" (Rachael) "Is it going to come back?"

(Cam) "It's hard not to worry or be frustrated or get sad." (Lizzie) "Is there an end to all this stress?" (Jason)

Ben, Jan, Lizzie, and Jason participated together in the first family research interview. The family was given the choice of whether they would like to come to the interview together or speak to me individually, or in smaller groups. After a careful discussion regarding the research study and consent forms, both parents signed the parental consent form (Appendix B); following this, both Lizzie and Jason signed the brother/sister assent form (Appendix C). The first research interview focused on the family's experience of living with childhood cancer. I did have some guiding questions that I used throughout the interviews (see Appendices E, F), but there was an effort not to conduct or direct the conversation, but to be responsive to the research topic and the thoughts/questions presented by family members during the process of the research conversation. What was particularly striking within this research interview was the depth of information that was shared by each family member about their experience of living with childhood cancer. The two siblings, Lizzie and Jason, shared information with me during that interview that they had not shared with their parents prior to the research interview. I will explore this phenomenon in greater depth in chapter nine, which focuses on the process of clinical intervention based on the IBM (Wright & Bell, 2009; Wright et al., 1996).

Not only did these family members learn new information about each other's illness experiences within the research interviews, but they seemed to have a deep curiosity, and appreciation for learning more about what the other family members had experienced, felt, and thought during the time of illness. The other surprising aspect of

this research interview for me as a researcher was the ability that these family members had to recall details of the clinical intervention at the FNU, and to speak to the impact that clinical intervention had made upon their lives. In part this was surprising because throughout the course of the clinical intervention the nursing team had struggled with not having a clearly identified focus for intervention. Throughout the videotapes of this clinical work, the nursing team had voiced an uncertainty about whether or not the clinical intervention had assisted this family in any meaningful way.

This first research interview lasted between two and three hours, and I was left with the impression that the family would have liked to have continued talking, if time had allowed. Each of the family members was eager to return for subsequent research interviews. During the second interview only Jan and Ben were present, while the third interview included the same four family members (Ben, Jan, Lizzie, and Jason) present in the first research interview.

Nurse Clinician. The nurse clinician who worked with this family was in the second year of her Master of Nursing program in Family Systems Nursing, and a novice Family Systems Nursing clinician. This was the first family that she had seen in the FNU. Her clinical background was focused in working with adult palliative care clients and their families in a community setting. The clinician was supported by a nursing team, and had live supervision of this clinical work by a faculty member who had expertise in both Family Systems Nursing, as well as the field of pediatric oncology.

The Second Research Family

The second research family first attended clinical sessions at the FNU in 1995. At that time, Karynn was 26 years old and a single mother. She had given birth to her

daughter Lauren when she was a teenager, and Lauren's biological father had never been actively involved in Lauren's life. In 1992, Lauren was diagnosed with a CNS tumor, and at the time of the first set of clinical sessions at the FNU, Lauren was receiving chemotherapy treatment. Over the course of her illness treatment she also received radiation, and underwent surgery. This family was initially referred to the FNU by their faith/spiritual community. The initial presenting problem was that Karynn wanted to learn how to have a more positive view of her situation in order to regain a sense of control and resume normal daily living. Within this clinical work, the family discussed the lack of support from extended family members, as well as their fears that Lauren may die. The family received four clinical sessions during 1995, and then returned to the FNU for one follow-up clinical session in 1997. At the time of the follow-up session in 1997, the nursing team learned that Lauren had a relapse of her tumor 11 months prior to that clinical session, and had been receiving monthly chemotherapy since that time. Also, Karynn was recovering from a recent struggle with clinical depression. When Lauren had initially been diagnosed, Karynn had been pursuing graduate studies, which she continued for some time into Lauren's illness treatment. Eventually, she did decide to leave graduate studies due to Lauren's ongoing illness, and the increasing medical needs that the family faced.

The family self-referred themselves for further clinical intervention at the FNU in September of 2004. At that time, Karynn had been re-married, and Lauren (21 years old) had become confined to a wheelchair at 15 years of age. Lauren was experiencing significant and ongoing medical complications related to the treatment she had received for her CNS tumor, and was residing in an extended care facility due to the intense

physical and medical needs which could no longer be met in the home environment. The transition that the family had faced from moving between the pediatric and adult health care system when Lauren turned 19 years of age had been particularly challenging and distressing for the family. Mike (new husband) and Karynn also had a new daughter, Izzie, who was 3 years old at the time of the 2004 clinical sessions. For the second set of clinical sessions, the presenting concern was Karynn's need for assistance in coping with Lauren's illness, including her fears that Lauren may die in the near future. Throughout the years of Lauren's illness, Karynn had been told three times that Lauren was not going to survive (during acute episodes of illness). Karynn had been struggling once more with clinical depression, as well as the care giving needs for her daughter Lauren. During the first clinical session, Karynn was asked the "one question question" (Wright & Bell, 2009, p. 99) and gave the following response: "Can I survive this life? Can I actually get through this? I want to feel I am in control of my life again. Is there some way I can view Lauren's illness as manageable?" The family received six clinical sessions between September 2004 and April of 2005. Karryn and Lauren attended the first session together, and then Karynn attended the majority of the clinical sessions alone. Her new husband Mike did attend the fourth clinical session in support of Karynn, but was not an active participant of the clinical work.

Karynn participated in two research interviews in June and July of 2009. When Karynn came for the first research interview, I shared with her that the FNU had closed in December of 2007. She expressed deep sadness when I gave her this information. She wanted to know why it had closed, whether there had been a lack of funding. I explained that Dr. Bell was no longer teaching in the Faculty of Nursing, and that there were many

aspects of the decision that I was not completely aware of. I explained that Dr. Bell was continuing on as the supervisor of my dissertation research, and that both she and Dr. Wright continued their work in new and different ways, speaking to nurses and other health care professionals nationally and internationally about their clinical practice and research in Family Systems Nursing.

Karynn shared with me that she felt honored to have her family's experience with the FNU and illness documented and researched in this way. She hoped that other families might be helped in their experiences with illness through this research. She expressed her willingness to do as many interviews with me as needed, and her eagerness to be part of the process. At the end of the research interview, when the audio-tape was turned off I expressed to Karynn how much I appreciated her willingness to participate in this research. She again said that she was glad to do them, even though it was scary and painful to look back at how she had been suffering during the years that she came to the FNU. She also spoke about how the one thing she would do differently would be to have continued the pursuit of her academic goals/plans despite what was happening with Lauren and her illness. She wished that she had continued to follow that path, despite illness.

Nurse Clinician. The nurse clinician who worked with this family was in the second year of her Master of Nursing program in Family Systems Nursing, and a novice Family Systems Nurse clinician. Her clinical practice history was working with gerontology clients and their families. The clinician was supported by a nursing team, and had live supervision of this clinical work by two faculty members who had extensive

theoretical, research, and practice expertise in relation to Family Systems Nursing and the IBM (Wright & Bell, 2009; Wright et al., 1996).

The Third Research Family

The third research family was seen at the FNU for three clinical sessions between February and April in 1998. At the time of the clinical intervention, Mark (father) was 32 years old, and Isobel (mother) was 31 years old. The couple had met in high school, and had married five years later, in 1991. Their son Andrew (then 6 years old) had been diagnosed with a rare CNS tumor and at the time of the clinical sessions the parents had chosen to pursue complementary therapy following his initial surgery. The progression of Andrew's tumor was being followed through MRI scans during the time of the clinical intervention at the FNU. This family pursued clinical intervention at the FNU to receive help in dealing with Andrew's illness, and expressed their worry about how the illness was affecting their children. When the nurse clinician asked them the "one question question" (Wright & Bell, 2009, p. 99), these were their responses: "I know how to help myself, and Mark is responsible for himself. What can I do to help the kids cope?" (Isobel) and "What would make it easier for them?" (Mark).

This family was referred to the FNU by a counselor at a community counseling centre. Mark and Isobel had been receiving support from this community counseling centre for a period of seven years. There they had both participated in couple counseling as well as various psycho-educational courses (communication, stress management, anger management, and self-esteem). Both parents spoke very highly of the counseling support they had received from this agency. They explained that given Andrew's recent diagnosis,

their counselor at the community counseling centre had felt that a referral to the FNU was warranted for further family support related to Andrew's life-threatening illness.

Mark described his relationship with his father as challenging, but explained that he, Isobel, and the children remained connected with his family, visiting together about once a month. Isobel's family of origin lived in Calgary, her father had recently died of lung cancer and he had received his diagnosis not more than a month before Andrew was diagnosed. At the time of the family intervention, she described her relationship with her mother as close; they shared frequent phone contact and her mother babysat the children once or twice a week. Isobel also had a sister in a city in Alberta and a brother who still lived in Calgary. Both parents described a strong social support network of friends and family members. They also reported having received strong support from the community and school in relation to Andrew's cancer diagnosis.

Isobel participated in two research interviews in November of 2009. Within the time that had elapsed between 1998 and the time of the research interviews, she and Mark (father) had divorced; she had re-married, and had had more children with her new husband. We met at her home, and she willingly participated in the research study. Despite her divorce from Mark, they remain good friends and she spoke well of him throughout the research interviews. I found that within these two research interviews in particular, it was helpful to have the clinical videotape clips prepared, as the time which had elapsed between the research interviews and the clinical intervention at the FNU had been prolonged. One of Isobel's reflections after viewing the clinical videotaped segments was increased compassion for her ex-husband Mark, for the uniqueness of his suffering in the context of living with Andrew's illness. During our research interviews,

she in a similar way to other family members who participated in this research, shed many tears, and openly spoke about the continuing uncertainty of the family's experience with Andrew's illness. The winter prior to our research interviews Andrew had been hospitalized for an infection, and he had nearly died during that illness episode. For many years the family pursued various complementary therapy treatments both nationally and internationally, but at the time that we met for our research interviews, the family and Andrew had made the decision to stop pursuing further treatment and MRI scanning. Isobel shared with me that Andrew was attending post-secondary education, and lived away from home. He continues to face medical challenges, and became confined to a wheelchair after becoming paralyzed following a surgery in the United States. Isobel also spoke openly about how the deepening of her Christian faith had helped her cope with living with Andrew's illness; her faith has provided her with great strength, and she now trusts that whatever happens in the future is part of God's plan for Andrew and her family.

Nurse Clinician. The nurse clinician who worked with this family was completing her doctoral studies in Family Systems Nursing at the time of this clinical work. She brought extensive theoretical, research, and practice expertise in relation to Family Systems Nursing and the IBM (Wright & Bell, 2009; Wright et al., 1996). Additionally, she had a clinical history of practicing as a family support nurse with children and families living with childhood cancer. Subsequent to this clinical work she completed her doctoral studies, and then took on a teaching and clinical supervision role with graduate students who were studying this particular approach to Family Systems Nursing. Presently, she has a research program which focuses on family-centred care and family intervention in the context of childhood cancer.

Concluding Thoughts

Within this chapter, I have provided an introduction to the family members and nurse clinicians who agreed to participate in this dissertation research. In the next chapter I will begin to share the interpretive findings from the analysis of the videotaped clinical work, as well as the research interviews with these research participants. Within the first interpretive chapter, I will focus on family suffering, the profound changes that family members experience in family roles, relationships, and routines following the diagnosis of cancer. Also discussed will be the loss of family normalcy, and the loss of home, a grounding or sense of safety and security in life, as well as the unique experiences of suffering that exist for parents, brothers and sisters, and the ill child.

CHAPTER SEVEN: ILLNESS SUFFERING IN CHILDHOOD CANCER

No Longer at Home in the World: The Loss of Place, Relationship, and Meaning

"Your child has cancer." These are the words that no parent ever plans on hearing; they are beyond what is imaginable for families who live everyday, normal lives. Parents who live normal lives wake each morning, make breakfast, and prepare their children for another day of school. What is taken for granted in this picture of family life? Most of us live with the assumption that children will enjoy happy, healthy, carefree lives, at least until they reach adulthood. We assume that the young, those who are filled with the promise of more life to come, will be spared from encountering illness and death. The experiences of illness and death are meant to meet us in the latter part of life, or so we would think.

> *Jason (12 year old brother): I didn't really know a lot about cancer, I kind of knew that…I saw like on movies, and I knew that it was a really, really bad disease. But until you experience it, you'll never be prepared for it, it's a fact of life. So, I thought, "oh, in the movies, he's gonna be in the hospital for like two two days, and have a little blood taken"…Then it kind of struck me, more like six months, almost dying, surgery very often.*

The Fall of the Curtain

What does it mean to live as a family, a mother, a father, a brother, sister, or sick child, in the presence of cancer? For each of the families who participated in this research, the entrance of illness into their lives was unexpected and unplanned; it brought profound, life-altering changes.

> *Ben (father): The day the phone call came, it remains as sharp as ever in my memory, I mean the smells, the flavors, the cold weather outside because it was January. It just is a very vivid day. Up until that day, life was absolutely fantastic."*

It is as if there is a line in the sand drawn: on one side, life before illness, and on the other, life after the words tumor, and cancer. For each of these families, following diagnosis, they entered an unknown and frightening world; a place in which what was once normal was lost.

> *Ben (father): Going through six months of a hiatus of your life, and for me it turned out to be a year. Like I stopped working and all that. Since that time, it's been an uphill climb, trying to find, what is normal? Or what was normal, because what was normal can't be now, because of what cancer did (father).*

This father gives the reader a glimpse of one of the many illness losses that are experienced when cancer enters family life. Yet, what do we mean by normal? What is normalcy, and how do we understand that idea? During the analysis and writing of this dissertation, I found myself exploring this idea of 'normal' with a mother whose child had died of cancer. I shared with her that I had been wondering how we had come to this idea of 'normal' in human life, and particularly to its loss when children have a life-threatening illness. I had been wondering whether normalcy is an illusion, something that we strive for, yet never really achieve in life. She then offered me an intriguing idea: that maybe 'normal' is really about what we know. Maybe we come to consider something normal, because it is what we know and understand of the world. She shared her belief that families who have children diagnosed with cancer, come to know something different about the world. What they know about the meaning of parenthood, what they know of what it means to be a child in the world, what they know of safety, security, joy and sorrow, changes irrevocably. With this changed knowing, the normal that once was, is lost. This mother had met many parents who were waiting to return to normal one day, after treatment was over. She shared her belief that often families do not understand that

they will never be able to return to normal, because what they know has changed, and they will therefore, never be the same.

Within this research, as in previous research findings (Björk et al., 2009; Clarke-Steffen, 1990, 1993, 1997; Fletcher, 2010; Kelly & Ganong, 2011; McCubbin et al., 2002; McGrath et al., 2005; Moody et al., 2006; Nicholas et al., 2009; Patterson et al., 2004; Woodgate 2001, 2006a), family members spoke of the loss of family routines, rituals, and roles, as well as changes in family relationships. During one of the research interviews, an 11 year old sister shared with her parents the profound changes she had experienced in family life after her brother began treatment for cancer:

> *Lizzie (sister): I never got to see him, or you guys* [spoken to her parents, who were present with us in the research interview]. *We only got to see him twice, basically otherwise Rachael (older sister) was our mom...for the six months, while you guys were gone. I had a new step mom...I just lost my parents to something.*

This family had come to the Family Nursing Unit (FNU) four years prior to the research interviews for this doctoral dissertation. At the time of the clinical work at the FNU, both of the siblings interviewed for the research were of a young age, and had done very little talking within the clinical sessions. In fact, they attended only two of the five sessions that this family received at the FNU. Yet, during the research interviews, they were very open and eager to speak about their experiences with cancer and the FNU. Lizzie shared that she and her brother felt like they were excluded from the family circle during the time that Cam was receiving cancer treatment.

> *Lizzie (sister): I felt out of the circle, right away, as soon as they got that phone call, and they told Cameron he had to go back to the hospital, and they wouldn't tell us...that's when I felt...out of the circle. I felt like I got kicked out of the house.*

For these parents, this was the first time they had heard their children speak so openly about how deeply they had been impacted by the changes in family life following diagnosis. This knowledge came four years following their clinical work at the FNU. After hearing the children's responses, Ben (father) shared one of his reflections about coming to the FNU:

> *Ben: I think that's the first crack* [coming to the FNU]*...as you kind of come out of the cancer problem, wow, yeah, okay...we had all these people that, somehow...the curtain closed, and they were excluded.*

The curtain closed, the ill child and his parents on one side, and on the other, the brothers and sisters in this family. As Ben said these words, I had an image of a theatrical stage, with a heavy, thick, velvet red curtain slowly coming down on the scene of the stage. A theatrical play comes in different acts; was the act of this play over? Had they known the curtain was coming down, that life was about to change so profoundly? Until this family came and spoke to the nurses at the FNU, the parents seemed to be unaware that the curtain had fallen, that there had been a separation or split within the family unit. This experience of splitting or separation within the family, of distinct family groups developing within the family unit in the context of childhood cancer has also been reported by other researchers (Björk et al., 2005, 2009; Brody & Simmons, 2007; Koch, 1985; Leavitt et al., 1999; McCubbin et al., 2002; McGrath, 2001a; McGrath et al., 2004; Mercer & Ritchie, 1997; Nicholas et al., 2009; Patterson et al., 2004; Woodgate 2001, 2003, 2006a; Woodgate & Degner, 2004; Woodgate et al., 2003; Yeh, 2003; Young, Dixon-Woods, Findlay, et al., 2002).

The word curtain is related to the term curtain-wall, and is defined as "a cloth or metal concealing the stage," or "restricting the spread of fire," "the close of a scene," "a

protective barrier in general, as the fire of many guns directed along a certain line to prevent the passage of an enemy (also called curtain-fire)" (Geddie, 1961, p. 259). So within the word 'curtain,' we find beginning hints of protection from an enemy, protection from harm, protection from a fire. Was the closing of the curtain meant to protect these children from the experience of cancer, from sadness, grief, anguish, and anger, from illness suffering? Could the curtain contain the fire of suffering?

> *Jan (mother): We were actually trying to protect them from some of the sorrow, some of the tragedy and pain and hardship that was going on there…*

Lizzie did not feel protected:

> *Lizzie (sister): …it passes on to you…and even if you do protect us from it, it will still come back onto us.*

Lizzie and Jason felt isolated and confused; they did not understand why they could not spend more time at home, in their own house, and why their parents often would not talk with them when they came home from the hospital.

> *Jason (brother): The problem is, that…those two* [referring to his parents who were present in the research interview], *and Cameron, were experiencing it, the most…I was kind of kept in the dark. I really had no idea what was going on. And then…when cancer stopped…everyone changed. I changed, Rachael was changed, mom was changed, dad was changed. Lizzie was changed, everyone was changed, and, we could never be the same people again, we could never be the same family again.*

For this brother and sister, there was a sudden and profound change in family life, which included changes to the hierarchical status of family members. Rather than being equal in status with all other children in the family, suddenly the ill child was granted a heightened status because of his illness. The mother, father, and ill child formed one family group within the family unit, with the younger and older siblings forming another family group. Due the demands, worries, fears, and energy required to manage the

treatment for cancer, the family group of ill child and parents appeared to take on a

higher status, importance, and hierarchical position within family life.

The House Disappeared

The isolation, fear, loss of home and relationship, as well as the hovering threat of

death, found expression in a nightmare that this sister had during cancer treatment:

> *Lizzie(sister): I had one (dream), I remember it very well...I couldn't sleep the rest of the night after it. I had a nightmare that...I got dropped off by the Metcalfe's* [family friends] *after...school. They were dropping me off because my parents were looking after Cameron. We came home, and Jason* (brother) *was there too. And I was walking up the front steps, and the house disappeared. But dad, Jason, and Cameron were all still there...and so was my mom.*

> *Ben (father): Sense of home and connectedness, yeah...wow.*

> *Lizzie: And, it disappeared. And then, there were these black people in robes, going around my parents, and then they disappeared (her family). And then, everything went, it was black, and these people in black robes kept appearing everywhere. And I remember screaming, and sitting up, and couldn't go back to sleep, cause I was afraid they were going to pop out.*

Lizzie had shared this nightmare with me during my first research interview with her,

Jason (brother), and both parents. When I met with the four family members for a later

interviewer, I asked Lizzie if she could tell me what she thought this dream had meant:

> *Lizzie: Well, when the house disappeared I thought it was maybe, like...it was on fire...he wasn't there anymore (Cameron, the ill child)...and when my parents disappeared, I thought...I was the only child left in the family, everyone moved on and forgot me...or they might have died or something. And I was left alone in this world to fend for myself and I just wanted to...crawl up in a ball and disappear myself...but I couldn't, cause I didn't know how...*

This was the first time that Lizzie's parents became aware that she had ever had a

nightmare that was so frightening, and her dad very quickly related it to the lack of

family connectedness during the time of treatment. Both parents were very quiet as the

children shared their experiences.

Jan (mother): Never, at any time, was that a motivation…

Ben (father): Our intent…

Jan: …to exclude anybody. But obviously, it…happens over time.

Ben: [spoken to Lizzie and Jason] *Well, it's not…that I wouldn't tell you …it's that I didn't understand at that time. Because I was walking with Cameron, and your mom, into the unknown.*

When I first heard and transcribed these words, I was struck with Ben's language, "*I was walking with Cameron, and your mom, into the unknown.*" Ben was not walking with the entire family into the unknown, only his wife and the ill child. How might we understand this? Why does this happen to families after diagnosis? How, as health care professionals, might we better assist families to walk forward into the unknown together as a family unit? How might we work to raise the curtain of cancer, facilitating ongoing relational connection despite the need for families to navigate an unknown and frightening new world?

No Longer at Home or Safe in the World

The loss of family normalcy has been described in previous research (Clarke-Steffen, 1990, 1993; 1997; McGrath 2001a; McGrath et al., 2005; Woodgate, 2001, 2006a). In Clarke-Steffen's (1993) model of family transition in response to the diagnosis of childhood cancer, families are described as entering a state of limbo following the fracturing of reality. Following this, there is a reconstruction of reality which leads to the establishment of a new normal, which is characterized by altered daily routines, uncertainty, and a different worldview. Similarly, within this research, the worldview of family members was profoundly challenged. Families experienced a loss of

normalcy, yet what also emerged within the research was the loss of home, and a longing to return home.

> Jan (mother, videotaped clinical session): Well it's coming back home after…it's just coming back home again, and getting into, I would not say that we are back into our routine as a family…I lost a bit of them out there.

In this family's second clinical session, an older sister similarly posed the following question for the nursing team: "when will we return to normal?"

Normalcy is a word that emerges again and again in the pediatric oncology research literature. Yet normalcy is a clinical word, a word created by professionals, a word that may not be enough, may not be able to hold or reflect adequately what happens in family life when cancer arrives. These phrases 'returning to normal,' 'coming back home,' stayed with me for months, they lived with me, and held a haunting quality. Within them, I could feel a deep longing, a homelessness, a search for home, a longing for the life that had been lost. Yet, what is home, what are we speaking of when we speak of the loss of home in the face of childhood cancer?

As I turned these words over in my mind, a yoga teacher introduced me to a book called "The Dance" (Mountain Dreamer, 2001). The author of this book is a counselor, she is not a researcher or academic who has studied human suffering. Yet, my sense in reading her writing was that she had walked beside many people who had experienced deep suffering in their lives. Something in the words she had written spoke to me about home, about longing, and also about spiritual pain:

> Facilitating workshops and retreats, I have heard literally thousands of prayers, in
>
> circles, in sweat lodges, in healings and ceremonies. I have heard prayers of
>
> gratitude and requests for relief from physical and emotional pain…I have heard

the prayers of Buddhists and Christians and Jews…and those who would not

identify with any group or tradition. And beneath all the differences in language,

all the variations in the specific human needs of the moment, I always hear the

same prayer, the same ache of the human soul. At the end of one such circle,

after hearing the prayers of the human hearts around me echoing my own, I said

very softly, "we all just want to go home." And the men and women around me

wept. (Mountain Dreamer, 2001, p. 113)

As I read these words, I found myself returning to Jan's (mother) words, to the

simultaneous longing for home and the difficulty in finding the way back home. This

sense of losing your home in the world, losing your grounding in life was also expressed

by another mother in this research:

> *Karynn [mother]: How do I be there for her when I'm panicked? It's very difficult
> …emotion and panic…It's difficult to know…like the ground. You need to be on
> ground that's firm...They need you to be on as firm a ground...Your footing has
> to be as firm as possible, so that you are able to feel like you can give your child
> what she needs. It's really, really important. I didn't really have that. And it
> would have made a big difference, if I'd had a bit more security footing
> emotionally.*

Ill children also struggled with the loss of safety and security in their lives. They

struggled with the knowledge that children do get cancer, they sometimes cannot be

spared from such a journey. Parents in this research not only had to work through their

own existential questions of why me? What now? How do we move forward? They also

needed to face questions from brothers, sisters, and their ill children. Jan (mother) shared

some of the questions that Cameron had for her as they journeyed through cancer

treatment:

> *Jan: I mean I know we're all fighting for life…the unfortunate thing, the reality
> is…Cameron had a hard time when Michael died* [a friend/roommate of

Cameron's on the inpatient cancer ward]... *"If there's a God, why is there any …why do kids get cancer? Why do kids die?" And so, he just couldn't…oh, he was mad…It's those kinds of questions that…why me? They're very difficult questions for adults…I could say, "why not?" I could come to peace…but he…*

Jan also spoke about listening to Cameron's questions as they sat together in the

oncology outpatient clinic:

> *Cameron* (ill child)*, to Jan* (mother)*: "What's that little baby got?" "Why did that baby…?"*
>
> *Jan: I remember I called that baby, Cam's baby. But a brand new baby, you're sitting in the clinic, waiting for treatment*

Could it be that what lies underneath the loss of normalcy, and the many changes

in family roles, routines, and relationships, is spiritual anguish for a lost home, for a sense

of grounding in life? An anguish and longing for a once felt sense of belonging, comfort,

shelter, and safety in the world? What does it mean to be at home in the world? What is it

to experience homelessness, a loss of home, in the context of life-threatening illness?

Thomas Attig (2001), a contemporary grief theorist, has written about the soul pain

experienced following a death. He connects soul pain to the experiences of homelessness,

a loss of grounding, an uprooting in life. For the families in this research, illness brought

a similar experience into their lives:

> Our suffering includes "soul pain." I use *soul* to refer to that within us that sinks
>
> roots into the world, makes itself at home in our surroundings, finds nourishment
>
> and sustenance in the here and now of everyday life. When we suffer soul pain,
>
> we feel uprooted. We feel homesick. We feel estranged within and alienated
>
> from the surrounding transformed by the death and our pain and anguish. We
>
> sense that we cannot find our way home to life as it was before the death. Fearing
>
> that we can never find our way to feeling at home again, we find it difficult to

care about anything at all. (p. 37)

In considering this soul pain, the loss of home, how do we understand home? Is home a physical place or is it relational? Perhaps home is embedded within both place and relationship. Wilson (2000) suggested that some aspects of home "may be found in the places we call home, it is our relationship both with places and the people we interact within them that help create our meaning of home" (p. 6). Home could be understood as a "loving embrace" (Wilson, 2000, p. 8). "Growing…touching new points of land…yet a family is like an island: a sustaining place of return nestled in the wide blue world, where one is at home with what one knows and celebrates" (Waller, 1995, p. 35). Home has also been connected to the idea of reach, of venturing out into the world, adventuring, followed by a return. Buttimer (1980) suggested that "like breathing in and out, most life forms need a *home* and *horizons of reach* outward from that home. The lived reciprocity of rest and movement, territory and range, security and adventure" (p. 170). How is home experienced when the venturing, the movement outwards, is unplanned, unexpected, and unwelcome, such as in a family's journey through treatment for childhood cancer? What if the security of home, the place that was once provided refuge, shelter, and protection from the world, cannot provide us with what it once did? Where does one find shelter then? And what clinical significance might the meaning of home hold for families living with cancer?

Literature and poetry also are embedded with meaning of place and home. In the novel *The Book of Negroes*, Lawrence Hill, a sociologist, writes a historically based story of Aminata Dialla, a young girl from West Africa who is captured and forced to walk in a coffle, entrapped and walking in a line of slaves, on her way to a frightening, unknown,

and far away land. Eventually she is taken to an indigo plantation in South Carolina where the midwifery knowledge that was passed on to her from her mother, helps her to survive. Throughout this story, Aminata longs to return to her home in Africa. As she contemplates the birth of her first child while she is a slave on an indigo plantation, Animata reflects on the home that awaits her unborn child:

> Where would home be for this child of mine? Africa? The indigo plantation? One seemed impossible, the other unacceptable. For this child of mine, home would be me. I would be home. I would be everything for this child until we went home together. (Hill, 2007, p. 179)

In a similar way, could families living with childhood cancer, families whose physical space of home has been irrevocably altered, find home in the relationships they share with one another? How, in the wake of a diagnosis of childhood cancer, do we as health care professionals assist families in finding a new normal, a new home, a sense of comfort, security, and a sense of belonging in family life? This research suggests that families do need to grieve the loss of home. Within chapters eight and nine of this thesis I will explore the ways in which illness grief and suffering in family life were addressed through particular Family Systems Nursing intervention practices at the FNU, University of Calgary. Within the clinical intervention studied, families were both assisted in grieving the loss of home, and in finding a new sense of place, relationship, and home in the world.

Parenting in the Presence of Childhood Cancer: The Illness Suffering of Mothers and Fathers

Earlier in this chapter, I explored the loss of normalcy in family life following the diagnosis of childhood cancer. That discussion included an exploration of how families

experienced the loss of home, meaning, place, and relationship. No longer at home in family life, as well as in the world, experiences of safety, belonging, and protection were lost. Now I will discuss some of the unique aspects of parental illness suffering in the context of childhood cancer.

At the core of parental illness suffering, there was an innate, instinctual drive to protect the ill child from harm, suffering, and death. In working to protect their child, parents carried an overwhelming responsibility in medical decision-making, and experienced a loss of confidence in their parenting abilities, which created uncertainty regarding how to best support and parent their children during illness, as well as in the years following treatment.

A Need to Respect the Sanctity of the Parent-Child Bond

The beginning of the cancer journey is extremely stressful for all members of the family. Parents face unique challenges at this time, they are the first ones told the news that their child has cancer, and in the midst of their shock, panic, and despair, they are asked to make serious and life-altering treatment decisions.

> *Ben (father): I understood the language when he said…Cam's late stage, high grade…and to me, those four words were…a death toll…and I can remember asking him, "can I have twenty four hours to think about this?" I've been four hours reading* [in reference to treatment consents]*…just overload. And he said, "Mr. McLaren, you don't have twenty-four hours. I expect Cameron to be dead in the next…forty eight hours…without treatment." What I didn't understand, was the treatment, why this, why that?*

For health care professionals, these are very difficult moments with families. Parents pass over the threshold into an unknown world when they learn that their child is seriously ill. Decisions about whether or not to consent to treatment must be faced within days, if not hours. Another parent in this research, who ultimately chose to pursue

alternative therapy for the treatment of her son's tumor, spoke of the responsibility she

shouldered in making treatment decisions for her son:

> *Isobel (mom): Before I had faith* [Isobel experienced a deepening of her Christian
> faith during the course of her son's treatment] *I felt like I was responsible...for the
> outcome. If I didn't research enough, or if I didn't get enough info, or make the
> right decisions, that it would be my fault that he died. And I totally carried that...
> if I don't do it right, he's going to die.*

In the research interview, Isobel spoke about the anger one oncologist expressed when

she and Mark (Andrew's father) refused to sign the consents for their son to receive

chemotherapy treatment. Andrew had a rare spinal tumor, which was difficult to diagnose.

Different oncology centers had different opinions on the type of tumor it was, and further,

there was limited evidence that chemotherapy would be effective in shrinking or curing

this type of tumor.

> *Isobel: When we were in the chemo part of it, I asked the doctor...he said "there's
> a tumor board in Germany that we're connected with...there's a tumor board in
> North America, we compare all our stuff...and this is what we want to do with
> Andrew." I think he said there's two hundred different chemo drugs..."there's
> three we want to use for Andrew," and I said, "so, in all the tumor boards, with
> all the patients represented there, have you ever seen a tumor like Andrew's...in
> child?" And he said, "no." And, "does that mean that the chemo drug they're
> choosing...he's a guinea pig?" And he didn't answer me. So, I took that as a yes
> ...they're just trying what they have...and I thought I was just not willing to do
> that. I wanted to be open to hearing what he had to say...I didn't just close off the
> info I wanted to hear both sides. I think it was the second appointment when he
> said, "you know, your son is going to die within two years...if you don't do this
> chemo." And that's...twelve years ago!*

This family pursued multiple types of alternative therapies to treat their son's

spinal tumor. Despite not receiving chemotherapy as recommended by the oncology team,

Andrew is still alive, twelve years after his spinal tumor was identified. He is presently

pursuing post-secondary education, and lives in residence.

Each of the parents interviewed for this research experienced difficulties in their

relationships with health care professionals as they worked through the decision-making

process at different points across the illness trajectory of childhood cancer. During his

first meeting with health care professionals to discuss Cameron's diagnosis and prognosis,

Ben felt that the sanctity of his parent-child bond with Cameron was violated:

> *Ben (father): The very first person I knew was Dr. Miller, and I thought he*
> *was...on my side. He's sitting on the other side of the table...lined up with all*
> *these "people." It's an oppositional setting...people are positioned across the*
> *table...we were highly ...we're not insulted...we were hurt, and it was a deep*
> *hurt...And what I think what they should do, rather than come on in an*
> *oppositional setting, "we're on this side of the table." That's not how you*
> *conduct negotiations...in the first place. It shouldn't be how you present...your*
> *son's medical condition. I'd kind of liked to have had Dr. Miller next to me,*
> *cause there's...there's probably times when I would have put my head on his*
> *shoulder, you know? As he was explaining this...cause I felt he was my*
> *friend...But I didn't know all these other characters...I learned later who one of*
> *them was...but none of that was introduced.*
>
> *Jan (mother): So just people in the room...they didn't know to introduce*
> *themselves to us.*
>
> *Ben: ...And I kind of felt violated...the sanctity of being Cam's dad...and as a dad,*
> *I want to make the right decision for my child...*

How might we understand the violation in the parent-child relationship that this

father speaks of? The word *sanctity* dates back to 1394, and is derived from the Old

French *sanctité,* and the Latin *sanctitatem,* which means "holiness or sacredness," and the

word *sacred* comes from the Latin *saceres,* "which connects to the base *saq,* meaning to

"bind, enclose, protect" (http://www.etymonline.com/index.php?search=sacred, May 2,

2009, 12:10pm). Sanctity, the sanctity of this parent-child relationship is linked

etymologically to the concept of protection. Here this father experienced a violation of

the sanctity of the parental role he had been given when Cameron became his child.

These parents needed to slowly come to terms with their inability as parents to spare Cameron from the painful and distressing experience that was ahead of him.

Gadamer (1989) suggested that although "parents may try to spare their children from undergoing certain experiences, experience as a whole is not something that anyone can be spared" (p. 356).

Experience is experience of human finitude. The truly experienced person is one who has taken this to heart, who knows that he is master neither of time nor the future. The experienced man knows that all foresight is limited and all plans uncertain. (Gadamer, 1989, p. 356)

What this experience asked of these parents was that they face the human finitude of human life, as well as finitude of the life of their young son. They had to come to understand that they could not protect Cameron or their family from the experience that was about to unfold. Just to be in the presence of the health care team, to be entering a conversation about treatment choices for their child's cancer, required them to face this experience. In this facing of experience, they felt that the one professional whom they had worked with closely, the doctor whom they knew and trusted, the doctor they considered a friend, chose an oppositional position by sitting with the other professionals on one side of the table, across from themselves. This was further complicated by an error of omission: the other professionals present, new to this family, did not introduce themselves.

What is at play in this experience of violation? How did these health care professionals contribute to the experience of violation? These professionals are responsible for the care of many children and families, and there are great demands on

their time and energy. Having sat in many meetings such as this one over many years of my own nursing practice, I am also aware that professionals carry an emotional burden, the burden of knowing what this news could mean for this child, and these parents, who love him so deeply. It is a very painful experience to be in the presence of such suffering, to be the bearer of such news.

Yet, not to introduce yourself, how can we understand this, and also the perception of opposition these parents were left with, the hurt that they experienced in this important encounter? Frank (2004), in his discussion of the need for a renewal of generosity in medicine and illness, articulated the philosophical thoughts of Lévinas on the moral obligation we hold to see another's face in life, and in practice. Frank suggested that this is what is required in health care practice if generosity is to be renewed within clinical relationships. "To see the other's face is to recognize that other as needing me and to feel chosen in the primacy of my obligation to meet that need" (Frank, 2004, p. 28). Frank noted that for Lévinas, this ethical obligation to the face is found even in the "mundane injunctions to be nice to people" (p. 49). For Lévinas, even in the word *bonjour,* in the greeting of another, there is a benediction, as well as an act of purposely making oneself available for the other. Lévinas (2001) has explained what he intends when he speaks of the face:

> The face…is like a being's exposure to death; the without-defense, the nudity and
> the misery of the other. It is also the commandment to take the other upon oneself,
> not to let him alone…If you conceive of the face as the object of a photographer,
> of course you are dealing with an object like any other object. But if you
> *encounter* the face, responsibility arises in the strangeness of the other and his

misery. The face offers itself to your compassion and to your obligation. (p. 48)

The professionals in this meeting did not open themselves to encountering the face of the other, these parents who sat at the beginning of their journey with cancer. What was lost in failing to encounter their faces was deeper than the loss of kindness or politeness. This was a missed opportunity to create a genuine human bond between the family and professional caregivers.

> In human relations the important thing is, as we have seen, to experience the Thou truly as a Thou [as another] – i.e., not to overlook his claim but to let him really say something to us. Here is where openness belongs…Without such openness to one another there is no genuine human bond. Belonging together always also means being able to listen to one another…Openness to the other, then, involves recognizing that I myself must accept things that are against me, even though no one else forces me to do so. (Gadamer, 1989, p. 361)

Jan (mother) further articulated her experience of being unheard as a parent during her son's treatment:

> *Jan (mother): There was a time I remember…I think I literally had to say…even though I signed over…the care of my son to you...he's still is my son [*with emphasis]*, and he also has been my son for 12 years...you've had him for 12 days or so...if he's reacting this way to pain* [Cameron expressed anger, frustration and aggression throughout his cancer treatment]*…this is not right... because this is not how he's ever reacted to pain in his life before. So you need to hear me…as a parent. And sometimes they just, well, they get professional...and it's like, "I know"* [with emphasis].

This family, as well as others in this research, repeatedly spoke of their experiences of not being heard by health care professionals. During Cameron's treatment for cancer, no professional would acknowledge that Cameron's distress which was expressed as anger, physical aggression, and frustration, was beyond what was expected.

This family was told that it would resolve in time without professional intervention.

During his treatment, Cameron spoke to his mom about the anger that would well up

inside him. Cameron did not understand or know what to do with the anger he

experienced:

> *Jan (mother): I climbed up beside him, and Cam said to me, "you know mom I can hurt you." And I said, "I know you can," I said, "you're getting to be a fine, young man." He said, "but I don't want to hurt you." I said, "I know that too, Cam, I know you don't want to hurt…" But he said, "something wells up inside me, and I can't stop it, and I don't know what to do." And again, when I shared this with people* [referring to health care professionals]*, "oh well, it'll go away."*

These parents asked about family therapy, and post-traumatic stress syndrome,

but they were told Cameron's anger would resolve.

> *Jan (mother): We asked the day that we were leaving the hospital if somebody would check Cameron for post-traumatic, traumatic… "Oh, it will work itself out." But again, that's where…if there's anything that your, your paper…notes it should note that good old saying again, "we're the parent, we've lived with this child for twelve years…who would know better than us if there was some dramatic change in that child's life"*

Following cancer treatment, Cameron was diagnosed with post-traumatic stress syndrome

after he became suicidal. At the time of my research interviews with this family, he was

being treated by a pediatric psychiatrist.

Becoming a Parent of a Seriously Ill Child: A Loss of Familiarity, Assurance, and Confidence in Parenting

For all of the parents in this research, the occasion of serious, life-threatening

illness acted as an interruption to the way they understood themselves as parents, and the

way they approached their parenting. Gadamer (1989) invoked the German word

Erfahrung (experience) in his articulation of the nature of experience. He argued that

experience is something one undergoes, it is understood as something that has to be

suffered, and it is in that suffering that one gains an understanding of the presumptions or

assumptions that we have. To think of experience as something that is gained or mastered, is to be mistaken. Experience is not something you obtain, but rather, it is a process. Experience is something that one is had by, it is an event that happens to us (Gadamer, 1989).

For these parents, there was a process of becoming parents of children living in the presence of life-threatening illness. No longer could their parenting be unquestioned or *taken for granted.* In her study of the parenting experience of acting-out adolescents, Binding (2006) noted a similar loss of *taken for granted* parenting:

Most of the time parents are not called upon to question or to reason concerning their parenting…At times parents may step back to reflect on their parenting, but for the most part parenting consists of a certain ebb and flow within family life. Parents generally do not have to articulate reasons for thinking in certain ways concerning their parenting, or for coming to particular decisions. Parenting can easily be *taken for granted.* Gadamer (1989) stated that experience is constantly being confirmed; in the experience of parenting, this is the taken for granted parenting. When the *every-dayness* of parenting experience is not confirmed, it stands out and becomes a different experience. (Binding, 2006, p. 64)

For the parents in this research, the illness experience was an event that challenged the *every-dayness, taken for granted* nature of their parenting. It called into question their deeply held beliefs and practices about parenting. When they crossed the threshold into the world of illness, parents experienced a new uncertainty in their parenting, a loss of confidence in how best to support and parent the ill child, as well as

healthy siblings. One mother spoke about how her parenting was affected by the fear that

her child might die:

> *Karynn: I went from being authoritarian to permissive…I'll let you get away with anything and everything, because I'm so terrified you're going to die. And that… she picked up on… If I end up showing her…that I'm changing my parenting completely, because now I'm going to let you get away with everything…what am I telling her? She's bright enough to know at 11 years old. "My mom thinks I'm going to die."*

Parents could no longer continue parenting with a belief that they were able to protect

their child from harm. Prior to illness, parents held the belief that if they did all the right

things, were good parents, shielded their child from the difficulties of life, then their child

would remain happy and safe. The experience of illness forced parents to confront the

knowledge that parents cannot always protect their children from danger, from illnesses

such as cancer, from the possibility of death. Jan (mother) spoke to the interruption she

experienced:

> *Jan: Boy, it's a big reality check, in a lot of ways. Because you just…you're moving along and your kids are doing their things, and you keep going, and you …of course…they wear the bike helmets, and you do the sports, you give them lessons, to try and keep them from breaking their bones. And so you follow, all of the… natural laws, I guess, of preserving and keeping your children…and then …wham…they're hit with a…I mean I had people come and say the darndest things…"have you fed Cameron well all his life? Have you given him fresh tomatoes?"*

Karynn (mother) also spoke of the guilt that she experienced when her daughter was

diagnosed:

> *Karynn: The guilt is just…it's an ever present guilt, that, "oh my gosh, this is my child, somehow I'm to blame." And somehow…I brought her into this world so young, she doesn't have proper parents…you know?*

With the experience of illness, rather than facing questions such as which

extracurricular activities children should be enrolled in, or 'how can I help my child do

better in school next year?' parents were faced with questions about life and death.

Karynn, who was a single mother at the time of her daughter's diagnosis, spoke about

how the illness experience consumed both her and her child, becoming the focal part of

their lives.

> *Karryn: It was really hard for me to differentiate between Lauren being sick and Lauren being Lauren…it was pretty hard for me to keep the illness as being…not one in the same with Lauren* [Karynn began to cry]. *And I think that's been my biggest struggle as her mom.*

Karynn felt that she was not given the support and information that would have allowed

her to parent Lauren in a way that gave her a sense of her self beyond illness, a sense of

herself as capable, confident, and safe. Karynn did not receive the support and guidance

in her parenting that she needed. *"You see, I feel that I've harmed Lauren…inadvertently,*

but I did." Because of the fear and chaos that surrounded their experience with illness,

Karynn believes that Lauren was able to experience herself only as a sick person. Below,

Karynn speaks about what she felt she needed, what would have helped her parent more

effectively in the presence of illness:

> *Karryn: A social worker, a nurse, a doctor…to help me to understand it, so that I could be presenting this to her, and living ongoing with her in a way that, she didn't have to feel like, "oh my gosh, I'm nothing but a sick person...that's just who I am," …it consumed me, and it consumed her, because she had no one else to follow but me, I was the only one she could follow.*

A father spoke extensively of the suffering he experienced in relation to having to

restrain his child during the course of his son's cancer treatment, and the effect that had

on his experience of parenting. This father was eventually diagnosed with post-traumatic

stress syndrome, and suffered a severe and prolonged depression following his son's

cancer treatment. Here he describes the experience of restraining Cameron in order to get

him to the operating room for surgery:

Ben: We fought from his hospital room, all the way into the elevator, and at one point they actually had a security guard accompanying us...and so you think, "what do people think about what kind of father I am?" I'm fighting this kid, like why couldn't we have given him a shot of Ativan in his hospital room? Calmed him down... instead of having this fight. And I had the security guard, I had a nurse, I had my wife, and I am fighting him, getting him into the elevator...We get off on the operating room floor, and this one time, there was this fantastic anesthetist, and he came out, cause I could not get him through the door...he seemed to be an octopus. He [the anesthetist] *came out, and he came up as I was spreading Cameron, putting Cameron in a bear hug. And I happened to notice that he had a shot in his hand, and he very quickly slipped it into Cameron's broviac IV...and Cam was fighting so hard, that didn't even...Cam fought the anesthetic, and stayed awake. And the doctor told the nurse, "go get another one." And Cam was still fighting me, trying to push me away, trying to get out, and it wasn't until the second one was administered that he finally collapsed... into the anesthesiologist's arms, and he and I put him on a gurney, and they took him into surgery...that was a struggle. Every operation, every IT* [chemotherapy injected into the intrathecal space].

It was during these experiences that this father felt he most needed help as a parent, help that for the most part was not available to him, his son, or his wife. How do you parent a child in such distress? This is an experience that no parent is prepared for, it moves beyond the boundaries of what parents face, or even imagine facing, in everyday life.

When a Brave Face Cannot Be Found: The Legacy of Unaddressed Anger and Trauma

As I listened to the words of Jan and Ben (parents) in the research interviews we shared, I was also invited to consider the other side of this parent-child relationship: the ill child. Ben and Jan spoke of the overwhelming anger that Cameron experienced after receiving a diagnosis of cancer. This emotion and the associated behaviors they described were almost beyond anger: there was a growing experience of rage within this young man. Could part of the rage that Cameron experienced have been related to the loss he

experienced in learning that the world is not as safe as once he believed it was, to

learning that his parents were not able to protect him from becoming seriously ill?

> *Jan (mother): And within twenty-four hours, Cameron was going for another surgery...And Cam says, I don't want any of this," he literally said, "I don't want any of this." So, within twenty-four hours he's...saying "I don't get what's going on here, what's going on?" The next thing he's being whipped off for surgery to have a broviac put in. And he comes back, and the first thing he says is "you don't love me, I told you I don't want this." And, I remember saying, "but we do love you, because we love you we did this," and I could just see the blank stare in his face. And it was like I'd just, either he'd slapped me across the face or I'd slapped him across the face because there's no comprehension there, at all. And even as time progressed, and the fighting kept going on, I would take much time to go for a walk and think how I could get through to Cameron. And I remember half way on the journey just saying "Cam, you're born to live, you're born to live, and nobody's going to stand by and let you die when there's things that can be done, you're born to live." And again, Cameron listened, but I don't know if he understood or if he could really hear.*

In this writing, I acknowledge that not every child and parent suffers in this

manner. Every family and child is unique, yet in this research two of the three ill children

struggled with anger, aggression, and frustration which eventually led to diagnoses and

treatment for oppositional defiance disorder and/or post-traumatic stress syndrome.

There is growing evidence within the literature that ill children have the potential to

experience trauma within the course of cancer treatment (Kazak, 2005, 2006; Kazak et al.,

1997, 1999, 2007, 2009), and that family members are susceptible to secondary

traumatization in witnessing the distress experienced by their children (Kazak 2005,

2006; Kazak, Alderfer, Rourke et al., 2004; Kazak, Alderfer, Streisand, et al., 2004;

Kazak Boeving et al., 2005; Kazak Simms et al, 2005; Kazak et al., 1997, 1999). The

trauma that this child experienced was not recognized, or attended to until after treatment

ended. This attention did not occur until he reached the point where he was considering

ending his life. What effect did this have on family life? How did this affect Jan's

experience of herself as a parent?

> *Jan (mother): I guess my greatest concern, I always had with Cameron, was just so much antagonism, and so much anger and frustration. That takes something out of you as a parent...and it makes your own self-esteem a lot more precarious, not as solid and firm as before, because I couldn't do something...I couldn't stop him, and that really, really hurt me. It's just a lot of uncertainty...coping with behaviors...and an inadequacy to...because we tried to find Cameron help, and we couldn't get anybody to step up to that plate, to help us with him, during cancer, after cancer...there wasn't the resources.*

Cameron's anger continued, his anger came home with him. Within the research

interviews with this family, there was evidence of the anger spreading throughout the

home, throughout the relationships he shared at home, and then out into other areas of his

life, including school. Lizzie and Jason (siblings) spoke about how it was not their

brother who came home from the hospital, it was someone else.

> *Jason (brother): When I heard Cam* [ill child] *was coming home cause he's all better, I was like, yeah, yahoo...my brother's coming home, we're gonna party, have some fun...all that stuff. And when he came home, he was a different person.*

> *Lizzie: Yeah* [said softly, in the background].

> *Jason: He was really angry...more violent than I remember him. And, he took his hospital experience and like came...always fighted, and kind of always fighted everywhere. At home, at school, and he was like...I was really surprised. I like... "you didn't take home my brother, go back and get him!"*

Cameron's anger grew and grew, spreading throughout every area of his life.

This spread and invasion of anger in Cameron's life is similar in many ways to how

cancer physiologically invades and spreads throughout the body, eventually leading to

death if it is not stopped by chemotherapy and/or other treatments. Could this spread, the

spread of anger, been prevented? Are we as professionals primarily focused on a child's

compliance to treatment, rather than the spread of anger and other forms of suffering

throughout the child and family's life? Cameron had to endure the difficult treatment of cancer to stop the spread and invasion of cancer, to stop the death that would come without aggressive treatment. With this treatment, the anger welled up in him, spread, and invaded his life. Eventually, the anger brought him to the very point of death, to a place of considering suicide. His tumor was cured, and yet his emotional and spiritual life remained filled with deep suffering for many years following active treatment.

Concluding Thoughts

Within this first analysis chapter, I have begun an exploration of the illness suffering of family members in the context of childhood cancer. Illness suffering within this population appears to be highly complex, with unique experiences evident both between the research families interviewed, and within different family relationships or subsystem levels. There was evidence of illness suffering occurring at the family level, but also unique experiences of illness suffering within different family relationships, for example, parental suffering, the relationship shared by parents and their children (ill children as well as healthy siblings), as well as in the relationships shared by ill children and their brothers and sisters.

Similar to other qualitative research (Björk et al., 2005, 2009; Brody & Simmons, 2007; Koch, 1985; Leavitt et al., 1999; McCubbin et al., 2002; McGrath, 2001a; McGrath et al., 2004; Mercer & Ritchie, 1997; Nicholas et al., 2009; Patterson et al., 2004; Woodgate 2001, 2003, 2006a; Woodgate & Degner, 2004; Woodgate et al., 2003; Yeh, 2003; Young, Dixon-Woods, Findlay, et al., 2002), families experienced a splitting or separation of the family unit within illness: the ill child and parents/mother formed one group, leading to a relational separation from other family members such as fathers and

well sibings. Due to the central focus on illness in family life, there seemed to be an increased hierarchical status granted to the ill child and the parent(s) caring for the ill child. The ill child's suffering was placed at the forefront of family life with the illness suffering of parents, and that of the well siblings, almost becoming hidden or cloaked behind the wall of a curtain. These experiences of suffering were so intense and profound for the well siblings interviewed, that they reported feeling excluded from the family circle, experiencing the very loss of their parents for the duration of the treatment period. It was also intriguing that parents seemed to be somewhat unaware of these changes and their relational impact within the treatment period. For one research family, it was only during their participation in clinical intervention at the FNU that they came to see how deeply the illness experience had impacted the well brothers and sisters. This research raises the question of how, as health care professionals, we might help families to maintain relational connection despite the presence of illness in family life. How might families be assisted to walk forward into the unknown and frightening world of illness together as a family unit, rather than as separate or split family groups? One possibility is through clinical intervention that focuses on the illness suffering of the entire family unit.

The loss of family normalcy was also a distinct and defining feature of illness suffering at the family level. Although each family member experienced a profound loss of family normalcy, each had a very different and unique experience in relation to that loss. Similar to previous research, changes in family roles, relationships, and routines contributed to these experiences of loss. How this research extends understanding about the loss of family normalcy in the context of childhood cancer, is through the understanding of that loss as a deeper spiritual issue in which there is a loss of home, a

sense of homelessness, a yearning and longing to return home. One of the internalized questions that was asked by family members was "when will we be able to return to normal again?" Embedded in this question is a belief that it is still possible to return home, that one day when treatment ends, families can return to the life they once knew, a life in which there was a sense of safety, shelter, and grounding in life, a grounding of the soul itself. There is a need to address this deeper spiritual anguish, this longing to once again be at home in family life, and to create opportunities for family members to explore the possibility that it likely will not be possible to return to the life they once knew and loved. What is needed is an opportunity for families to grieve the loss of family normalcy, and the loss of home, within the context of living with cancer.

The illness suffering experienced by parents was unique, and was marked by an innate, instinctual drive to protect the ill child, and well siblings from harm, suffering, and death. As part of their parental role, mothers and fathers experienced an overwhelming responsibility in relation to medical decision-making, often believing that the choices they made would determine whether their child lived or died. What often enhanced the suffering that parents experienced in relation to medical decision making was the difficulty they experienced in their relationships with health care professionals, particularly in experiences of not being heard, understood, or listened to. At times, these experiences led them to feel that the very sacredness of the child-parent bond was violated by health care professionals. Further, parenting during and following illness was marked with uncertainty, a lack of confidence, and a questioning of parental decisions. Parents were unsure about how to best support and parent both ill children and their healthy brothers and sisters.

Parents reported asking the following internalized questions: why had this happened to their child, their family, and how might they best move forward? Other internalized questions reflected the doubt and uncertainty they experienced in parenting. For example, one father who needed to restrain his child for treatment procedures, asked himself what people thought about what kind of a father he was. Buried within this question may be wonderings and questions about how he had failed as a father. First, he had not been able to protect his child from cancer, and then he faced an inability to calm or comfort his child in the face of difficult treatment experiences. Health care professionals need to carefully consider how they involve parents in a child's care, and how care giving experiences might enhance illness suffering for parents, and invite further doubt into their experiences of parenting. Finally, parents not only struggled with the internalized questions they asked themselves, but also carried a double burden in hearing the questions of their children: "why do children have to get cancer?" "why do children have to die?" Their suffering as parents was enhanced by the uncertainty they experienced in how to address and answer their children's questions, particularly in relation to why children become ill.

Within the next chapter, I will further explore the experiences of loss and grief experienced by family members in the context of their illness suffering. It will be proposed that the multiple losses experienced by family members need to be better addressed within the field of childhood cancer. As well, I will begin an exploration of how the process of clinical intervention based on the IBM (Wright & Bell, 2009; Wright et al., 1996) assisted family members to grieve the losses they experienced within their

illness suffering, while simultaneously inviting them to embrace new possibilities for relational connection, strength, and healing.

CHAPTER EIGHT: ADDRESSING EXPERIENCES OF LOSS AND GRIEF

WITHIN ILLNESS SUFFERING

Traditionally, the word grief has been associated with experiences of death and bereavement. Death began to lay a popular claim to the language of grief with the rise of the death awareness movement in the 1960s (Neimeyer, 2001). This cultural shift led to the growing acknowledgement of the place of death within human experience (Neimeyer, 2001). Popular understandings of grief and death were guided largely by the Elizabeth Kubler-Ross's famous book, *Death and Dying* (1969). What has not been as well acknowledged or understood are the experiences of loss and grief within serious illness, and the presence of grief within the experience of human illness suffering. The very word 'suffer' means "to sustain loss" (Geddie, 1961, p. 1103). Etymologically, the word suffer dates back to 1225, meaning to bear, undergo, endure, carry, or be put under pain, death, punishment, judgment, or grief. A related word, 'sorrow,' finds its etymological roots in the Old English word *sorg,* meaning "grief, regret, trouble, care" (https://etymonline.com /index.php?search=sorrow). The word grief also dates back to 1225, meaning hardship or suffering (http://www.etymonline.com /index.php?search= grief). Thus, we could conclude that the very word suffer means to sustain loss; undergo, endure, bear, or carry grief.

Experiences of loss and grief are an integral part of illness suffering for family members living with childhood cancer. Some of the grief experienced by family members is anticipatory in nature, relating to the possibility of the ill child's death at some point in the future, but other experiences of grief do not have an anticipatory character. Rather,

those experiences of grief are associated with the losses which occur within and across the illness trajectory of childhood cancer.

Wright (2005) has previously researched illness suffering in the context of Family Systems Nursing intervention, and in her book *Spirituality, Suffering, and Illness: Ideas for Healing,* she offered the following definition of suffering:

> Physical, emotional, or spiritual anguish, pain, or distress. Experiences of suffering can include serious illness that alters one's life and relationships as one knew them; forced exclusion from everyday life; the strain of trying to endure; longing to love and be loved; acute or chronic pain; and conflict, anguish, or interference with love in relationships. (p. 3)

Interestingly, the words loss and grief do not appear in this definition of suffering; however, some of the emotions or experiences that are a part loss and grief have been articulated. For example, altered relationships, spiritual anguish, pain, and distress, the exclusion of family members from every day life, the experience of straining to endure, longing for love, as well as conflict and anguish. What might be at play in the absence of these words in relation to illness suffering? Within hermeneutics, the researcher is entreated to follow the trail of language, there is an acknowledgement that language has a living and historical character which must be considered:

> In language the order and structure of experience itself is originally formed and constantly changed. Language is the record of finitude not because the structure of human language is multifarious but because every language is constantly being formed and developed…[and with that development]…the more it expresses its experience of the world…Every word breaks forth as if from a center and is

related to a whole…Every word causes the whole of the language to which it

belongs to resonate and the whole worldview that underlies it to appear. Thus

every word, as the event of a moment, carries with it the unsaid, to which it is

related by responding and summoning. (Gadamer, 1989, pp. 457-458)

Within this chapter, I will explore the nature of illness grief experienced by the

families in this research. Here, I will attend to illness grief which is related to physical,

relational/psychosocial, and symbolic illness loss (Doka, 1989, 2002; Rando, 1984, 2000;

Roos, 2002), anticipatory grief (Rando 1984, 2000), and what I have called the survivor

grief of illness. The acknowledgement of the presence of loss and grief across diverse

human experiences, including the experience of serious and life-threatening illness, is not

entirely new; grief theorists (Doka, 1989, 2002; Martin & Doka, 2000; Rando, 1984,

2000; Roos, 2002) have challenged the traditional idea that loss and grief are associated

only with death. They have suggested that loss needs to be considered more broadly.

Doka (1989, 2002) was the first grief theorist to discuss the disenfranchisement of grief

in human life; he suggested that grief becomes disenfranchised when a "loss cannot be

openly acknowledged, socially validated, or publicly mourned" (Doka, 2002, p. xiii).

This research invites a consideration of how experiences of loss and grief within

illness have been disenfranchised within the field of childhood cancer. The possibility of

death has always been a sensitive and emotionally laden topic in the world of oncology.

With the growing advancement of complex treatment modalities, and new therapeutic

successes, the topics of death, loss, and grief have become increasingly marginal within

the childhood cancer experience. What further complicates the issue of attending to loss

and grief within the family experience of childhood cancer is that much of the evidence related to loss and grief has come from experiences of death and bereavement.

The illness grief described by family members in this research emphasized the need to attend more fully to the diverse experiences of grief that occur as a part of this illness experience, while simultaneously continuing to support families in the processes of family resilience, life restoration, and family adjustment to illness. I will suggest that health care professionals may be assisted in addressing the loss and grief experienced by families living with childhood cancer by employing theory and research from the field of death and bereavement. Within this chapter, I will also present clinical exemplars of Family Systems Nurses clinical practice based on the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996) in which clinicians attended to the illness suffering of family members, at least in part, by explicitly addressing their experiences of loss and grief.

Turning to Greek Mythology: The Return of Persephone

Figure 2. "The Return of Persephone," by Frederic Leighton, 1891, http://frederic-leighton.org/The-Return-of-Persephone-1891.html. Copyright 2002-2010 by www. Frederick-leighton.org. Reprinted with permission.

To understand these families' experiences of loss and grief, it may help to turn to Greek mythology and the mythic tale of the return of Persephone to her mother, Demeter, the goddess of August (Thury & Devinney, 2009). Persephone was the beautiful child of Zeus and Demeter, and one day she was gathering flowers in a beautiful meadow. As Persephone reached out to pick the daffodil, the Earth opened, and Hades, the Greek king of the underworld and god of the dead, sprang up and seized Persephone, taking her against her will. It was Persephone's mother, Demeter, who heard her daughter's screams, and filled with a mother's grief, she searched across the land and sea for the daughter she loved so deeply. Eventually, Demeter learns that her daughter has been abducted by

Hades. In her grief and desperation to save her daughter, Demeter refuses to bestow her favors upon the Earth. Because of this, Zeus entreats Hermes, who is known as an intermediary and messenger of the gods, to "win Hades over with gentle words, and bring Persephone out of misty darkness to light and among the gods, so that her mother might see her with her eyes and desist from anger" (p. 3). Hermes does return Persephone from the dark underworld to the arms of her mother (see Figure 2), but because Hades had cunningly placed a sweet tasting pomegranate seed in Persephone's hands, and forced her to eat it, she would from that time on be required to return to the underworld for a part of every year.

> And as Demeter still held her dear child in her arms,
> her mind suspected trickery, and in awful fear she withdrew
> from fondling her and forthwith asked her a question:
> "Child, when you were below, did you perchance partake
> of food? Speak out, that we both may know.
> If your answer is no, coming up from loathsome Hades,
> you shall dwell both with me and with father Kronion [Zeus]…
> Otherwise, you shall fly and go to the depths of the earth
> to dwell there a third of the seasons in the year,
> spending two seasons with me and the other immortals.
> Whenever the earth blooms with every kind of sweet-smelling
> springflower, you shall come up again from misty darkness,
> a great wonder for gods and mortal men.
> With what trick did the mighty All-receiver deceive you?"
> Facing her now, beautiful Persephone replied:
> "Surely, Mother, I shall tell you the whole truth.
> When Hermes, the helpful, swift messenger, came
> from father Zeus and the other heavenly dwellers…
> I myself sprang up for joy, but Aidoneus [Hades] slyly placed
> in my hands a pomegranate seed, sweet as honey to eat.
> Against my will and by force he made me taste it
> (Athanassakis, trans. 2004, p. 11, 12[1])

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[1]From *The Homeric hymns* (2nd ed.) (pp. 11, 12), by A. N. Athanassakis (Trans.), 2004, Baltimore, MD: John Hopkins University Press. Reprinted with permission.

As Persephone would be required to return to the underworld, to live in the presence of darkness for a part of each year, the families in this research had to face the possibility that their children may die, and also experienced a cascade of other illness-related losses. Within their experiences with illness, and in life after cancer treatment, there was evidence of family members moving back and forth between the realms of suffering, loss, and death with the realm of joy, hope, and new life. One mother, whose child is now a young woman, spoke about the fear she recently experienced when her daughter was hospitalized with liver failure. This young woman continues to experience chronic and complex medical complications following her treatment with radiation and chemotherapy:

> *Karynn: It surprised me, she was in the hospital recently...I was terrified again. ...It was like being back at the beginning of her illness...I had no idea what to expect...She had...liver failure...her kidneys shut down first, then her liver did...It was terrifying...because I had no idea what to expect...all the years she's been in and out of the hospital, like it happens so much...when she got sick this time...I was freaked out. Literally, "what do I do?"...I mean, do I bring someone in to say prayers over her, to bless her? It didn't seem like something she might come out of...it was really frightening.*

Just as Persephone was suddenly forced against her will to leave her life, her family, and the world that she loved, so the family members in this research experienced moments of leaving. They were asked to leave the world they once understood, to leave the family life they had known, and parents left the experience of parenting which had been known, familiar, and assumed. Yet, just as Persephone returns to her family, life, and the world of the gods, also reflected in these families' experiences were moments of returning. Returning to life, experiencing the beginning of a new family, and finding a new understanding about what it means to be a parent in the context of living with life-

threatening illness. The rhythmic movement back and forth between experiences of loss, and experiences of life showed themselves again and again.

This rhythmic movement between leaving, alienation, and return is also reflected in Stroebe and Schut's (1999; 2001, 2010) Dual Process of Coping with Bereavement (DPM). Within this conceptualization of grief, coping with bereavement involves a movement back and forth between orientations of loss and life restoration. Within this stressor specific model of bereavement, adaptation to loss requires that bereaved persons attend to the stressors of loss as well as stressors of life restoration. Within the loss orientation, the focus is on confronting and processing loss, whereas the life restoration orientation involves attending to the life changes that accompany loss. In life restoration, the bereaved engage in new activities, distract themselves from loss and grief, deny/avoid their grief, and focus on the development of new relationships, roles, and identities. Stroebe and Schut (1999, 2001, 2010) have proposed that optimal adaptation to loss over time requires an oscillation, or a cyclical movement between these two orientations. What is important in the eventual adaptation to loss is the balance between the processing of loss and attending to processes of life restoration.

Based on the family experiences of loss and grief which were a part of the illness suffering of families in this research, experiences which will be described in the latter section of this chapter, I suggest that the loss orientation within the DPM be modified for possible application in pediatric serious and life-threatening illness. The loss orientation would focus on processing the many different losses discussed within this thesis. Within pediatric life-threatening illness, and within clinical intervention with families in this research study, the focus was not on processing a death, but rather, on processing the

losses which were a part of having a child diagnosed and treated for a life-threatening

illness such as cancer. These included the loss of family normalcy and having a sense of

being at home in the world (previously described in the bereavement literature as the loss

of the assumptive world (Parkes, 1988)); physical, relational/psychosocial, and symbolic

losses (Martin & Doka, 2000; Rando, 1984, 2000; Roos, 2002), anticipatory grief (Rando,

1984, 2000); and illness survivor grief. Figure 3 illustrates the suggested modification of

the DPM for potential application within the field of childhood cancer.
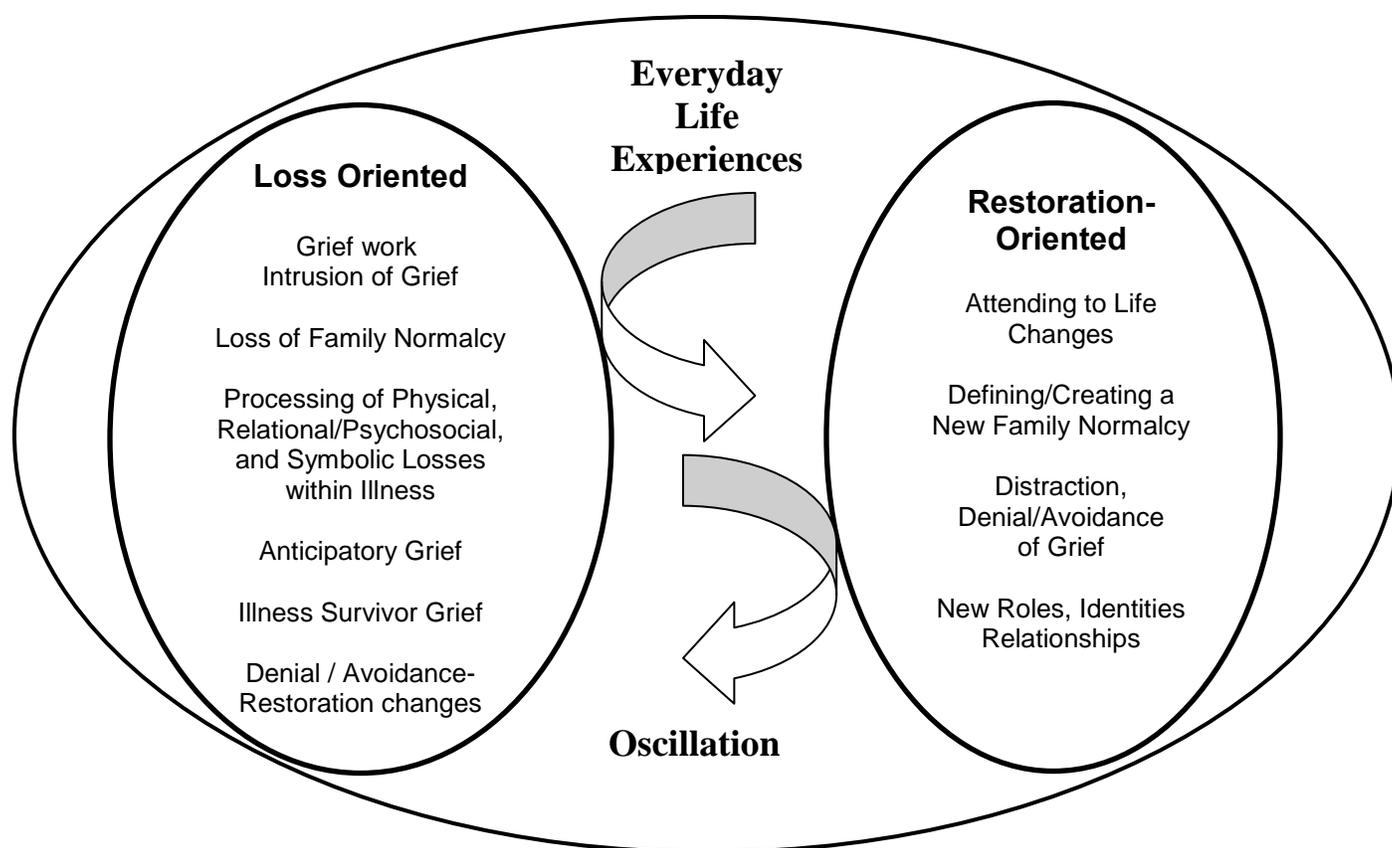
Figure 3. Adaptation of the Dual Process Model of Coping with Bereavement (DPM) (Stroebe & Schut, 1999) for Attending to Illness Grief within Pediatric Serious and Life-Threatening Illness[2]

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[2]From "The Dual Process Model of Coping with Bereavement: Rationale and description," By M. Stroebe and H. Schut, 1999, *Death Studies, 23,* p. 213. Copyright (1999) by M. Stroebe and H. Schut. Adapted with permission.

Within Stroebe and Schut's conceptualization of grief (1999, 2001, 2010) there is a call to understand the cyclical movement of grief between an orientation of loss, and that or life restoration. A focus on grief as movement is also evidenced in recent research emerging from the study of clinical intervention with bereaved families at the FNU (Moules et al., 2004). These authors have come to understand grief following bereavement a movement that involves a walk backwards into the past to a time when the one who has died was still physically present, while also attending to moving forward in life (Moules et al., 2004).

> Walking backwards seems to fit the movement associated with grief. The art of grieving requires the use of different muscles than we are used to using in our lives…Walking backwards allows the strengthening of part of ourselves that we were not aware of or did not have to use. It allows one the ability to look to the past and recall what was, and yet continue to move along. We do not see walking backwards as a permanent state…nor do we suggest that the bereaved should not ever look ahead and walk in more typical fashion, but what we are suggesting is that grief requires this occasional and periodic walk backwards. (Moules et al., 2004, p. 103)

The movement forward described in this research could be interpreted as holding a kinship with Stroebe and Schut's (1999, 2001, 2010) focus on life restoration, whereas the movement of walking backwards may be similar to the loss orientation. What may differ for families living with pediatric life-threatening illness, is that there will not be a walking backwards as experienced by the bereaved, but rather, in anticipatory grief, an

occasional walk forwards to a time in which the ill child may no longer be physically present, a time when death has occurred.

A Cascade of Losses: Illness Grief in Childhood Cancer

A Surreal Existence Following Diagnosis: Physical, Cognitive, Emotional, and Spiritual Experiences of Grief

Throughout this research, the responses of family members following the diagnosis of childhood cancer, and throughout the years of treatment included physical, cognitive, emotional, and spiritual responses that were similar to those which have been reported by the bereaved. For example, the bereaved often experience difficulties in cognition, including confusion. "Many newly bereaved people say their thinking is very confused, they can't seem to order their thoughts, they have difficulty concentrating or they forget things" (Worden, 2009, p. 42). Similar findings occurred for family members in this research study:

> *Isobel (mother): …first two years of constant terror…and I remember forgetting …I would forget appointments, and I'm not a person to forget appointments…and I would forget two or three and not even realize for a week…that I'd missed them. And I was like, "oh my goodness, I feel like I'm going insane," cause I can't even see what I'm missing, you know? And that was, kind of, a scary feeling…and driving and not realizing I've got there, and just…yeah, just brain on overload.*

Lizzie, one of the siblings who participated in this research, experienced significant difficulty with her school work during her brother's illness:

> *Jan (mother): I know that Lizzie had anxiety in a different way. Like, she was unable to focus on her studies, and her work…she just couldn't remember… …there was actually a period in that time where she quit reading…she just couldn't read anymore…she could hardly remember how to spell…*
>
> *Lizzie: I do…I do remember that. When I did that work…when I went to my friend's house for home schooling, I couldn't write at all…cause my hands were just shaking so.*

Family members also spoke about experiencing a state of shock following diagnosis:

Jan (mother): More than anything, when I first heard, it was…"I hear it, but I…I don't really believe it…cancer's not something that we really sit and expect… Cameron had been in there, and had had it out [surgery to remove his appendix]*, and nobody said anything…and so just to get a phone call out of the blue to say, "oh…we found some cancerous tumors, you need to bring him back," it's like… and so you just kind of start to operate in a sense of shock.*

Physical responses following diagnosis were also reported, both by parents and siblings.

These physical responses were strongly connected to the emotional and spiritual distress

experienced by family members:

Isobel (mother): I remember I'd wake up every day with a…stomach pain…just like a big knot. And you'd wake up kind of delirious and go…"what is my life again?" And then…remember every morning…all over again. So, being traumatized the moment you wake up, everyday. Cause you think you're dreaming, you know? I had no trouble sleeping, cause I'd be so dead exhausted…I just remember watching people, and thinking, "oh, I wish life was that simple." You know, watching kids play soccer, and wishing it was that simple…

One of the brothers who participated in this research, similarly spoke about the physical

responses he experienced during his brother's treatment for cancer:

Jason (brother): Well…I couldn't breathe, like, everything was…well, disappearing. Nothing was around, everything was changing, nothing was normal, everyone was scared, sick, hurting.

Ben (father): Jason suffered some anxiety at that time…

Jason: Yeah, I couldn't swallow. Like, I had…chicken nuggets…I took it, I bit in, I bit in, I chewed it, start to swallow, it wouldn't go down…it was stuck right there. So, I remember, using, I'd usually get like, two big glasses of…just to eat three chicken nuggets, because they wouldn't go down, so I had to force my food down.

Family members also experienced behavioral responses to loss, some of which

were similar to what has been reported by the bereaved (Worden, 2009). These included

sleeping and appetite disturbances, as well as disturbing and frightening nightmares.

Lizzie (sister): When I thought Jason [brother] *had nightmares…they were just about boogie men under the bed, or in the closet. And he would always come into*

my bed and wake me up, and he's like "can I sleep with you?" And I was, "fine." And he would always want me to hug him, and I would, and I'd be like, "tell me about your dreams." And he'd start talking…

For all of the families within this research, the entrance of childhood cancer brought a loss of safety and security, the questioning of their place in the world, which was accompanied by a loss of control. Many of the parents used metaphors to describe their experiences of suffering, metaphors which reflected the loss of control that they experienced when their child had been diagnosed with cancer.

> *Ben (father): I mean, I described it at the time* [during his clinical work with the nurses at the FNU]*…I think I used the word tsunami…I remember watching…two years ago now…that big one that hit Asia, that's exactly how I felt. You saw people being…you're absolutely powerless to stop this wave of water, there was nothing…and no matter how much you struggled you couldn't get out of it…you were at the mercy of a power that you didn't see, a power you didn't know, a power that you didn't understand, you did not know where it came from. And you know, there's changes in the family dynamics, there's changes in the personality there's changes in the personality dynamics of each one of the children…that's why I like the word tsunami, because a tsunami at sea, you don't even see it go by …and it's not until you're on the shore, when you think you've made it, that it hits you. And it's, it's unrelenting, and it doesn't end.*

Relational Loss: The Loss of Family Connection

Relational loss "refers to losing a relationship with someone to whom one has an attachment" (Martin & Doka, 2000, p. 12). Within this research, family members experienced multiple levels of relational loss, some of which were explored in chapter six of this thesis. All family relationships were profoundly affected by the presence of childhood life-threatening illness. In one of our research interviews, Lizzie (sister) used the metaphor of being lost in the jungle to express the loss of connection she felt with other members of her family following the entrance of cancer into family life:

> *Lizzie: I actually felt I was lost in a jungle when it started…I felt disconnected from the world…I was the only one in the house who survived on my own. I had to provide for myself…Why I picked the jungle…cause it's so easy to get*

> *disorientated and lost…and to be separated from…your guys, your family…*
> *and that's what it was like when Cameron was in the hospital…we all separated,*
> *and went our separate ways…and it's like a jungle, cause you don't know where*
> *they're going, and what house they live, and where …and you just have to try and*
> *find your way through it…to your family…and it's really* [emphasis] *difficult…*

Lizzie felt that even when she did have time to see her parents, she did not know them

anymore:

> *Lizzie: I also need to see my parents, cause like, I had a step mom for the last six*
> *months* [Lizzie is referring to her older sister Racheal who took over many of the
> care giving responsibilities at home for her younger siblings]…*And the only time*
> *we got to see our dad was in the morning for twenty minutes on the way over to*
> *…otherwise, basically, we didn't even talk on the way over there. They'd just sit*
> *in the car, there was absolute silence, like we didn't even know the person.*

For Jason (brother), the loss of his parent's presence at home led him to wonder whether

his parents still liked him:

> *Jason: By like, half way through, I felt "why aren't mom or dad coming to see*
> *me? You know, maybe they don't like me."…They were never home, I hardly see*
> *them, when I saw them, they hardly would talk, it was tough.*

As I discussed previously, some of the ill children from these research families

struggled with trauma and severe anger throughout their treatment for cancer. The ill

child's anger and fighting had a dramatic effect on the relationships that they shared with

family members. One mother spoke of the loss of the son she had dreamed she would

have, which represents both a relational and a symbolic illness loss:

> *Jan (mother): And his fighting* [the ill child]…*really the bottom line of it all…*
> *is fear…and anxiety, heh. But…I just think that that was not the boy that I…*
> *I gave them. You know, when we went in, and it's…not the boy that we would*
> *have ever have dreamed of…four years later.*

Symbolic Loss: The Loss of Dreams and Hopes

Symbolic loss has been defined as the loss of the "intangible, involving the loss of

a psychological or spiritual attachment such as the loss of one's dreams, hopes or faith"

(Martin & Doka, 2000, p. 12). Within this research, family members experienced a loss

of what was expected from life, the life they had dreamt for themselves, and each other

had been lost.

> *Jan (mother): I just think too, he was just in shock* [the ill child]… *"I have this life and now I have this life, I don't want this life, I just want…out of it. I'm petrified in it, I hate it, it hurts…just let me go. Because sometimes he* [ill child] *said, "just let me go, I just want to die."*

> *Ben (father): And I'd say, "absolutely not Cam." I remember one day he said …"dad, I think I'm going to die." And I said, "you're not." And I said, "everything there can possibly physically be done, is being done for you…to preserve your life." And I said, "and…if I have anything to do with it, you will not precede me in death. The natural order of this is for a son to bury his father." And I said, "I am not gonna bury my son." …it was a very intimate moment when we were talking about that.*

Parents also experienced significant losses related the goals they had held for their own

lives. For Karynn, a single mother at the time of Lauren's diagnosis and treatment, one of

the most painful losses she experienced was surrendering her hopes and plans to

complete graduate school. Karryn's academic goals had given her a sense of achievement,

a sense of moving forward despite illness, and allowed her to feel like she had some

control.

> *Karynn: …leaving school was a mistake…I think that was a really strong…tool for me to stay on track…achieving in school...by letting go of it, I let go of my sense of control altogether…*[If I'd stayed in school]*…I would have been able to have more choices, And I think it would have kept me more…my mental, emotional…state, I think I would have been better off…if I ever had to give advice to someone…"Keep working at the goals and the dreams, an the aspirations that you have. Don't…let go of who you are. Don't let this consume you."*

The Death of Fellow Cancer Patients: When Is It My Turn?

One of the unique losses that family members experience in living with childhood

cancer is the death of fellow patients within the hematology/oncology treatment program.

Children who are receiving treatment often get to know each other well, seeing each other on the inpatient unit, in the outpatient clinic, as well as at summer camp and community events arranged for families by hospital staff as well as childhood cancer foundations. Parents and healthy siblings also develop friendships with other ill children and members of their families. The death of fellow patients invited experiences of grief related to the death of a friend and fellow cancer patient, but simultaneously invited experiences of anticipatory grief. With these deaths, family members asked themselves questions about if and when their own child might die.

> *Jan (mother): I just remember the first time somebody died I asked...I think I was just as shocked too, like you know...it was so hard.*

> *Ben (father): And like too, you'd see them, the kids would die or whatever, and sometimes early at two o'clock in the morning, they'd take them out of the room, if they'd passed on...I remember seeing them...And I'd sit there and I'd ask myself, "when is it my turn?"*

Anticipatory Grief or Illness Grief?

From her research on anticipatory grief and mourning, Rando (1984, 2000) has articulated the importance of attending to the wide range of losses that can be experienced within life-threatening illness. Rando (2000) proposed that anticipatory mourning includes more than grieving an anticipated, expected, eventual or coming death. She defined anticipatory mourning in the following manner:

> Anticipatory mourning is the phenomenon encompassing seven generic operations (grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing, conflicting demands, and facilitating an appropriate death) that, within a context of adaptational demands caused by experiences of loss and trauma, is stimulated in response to the awareness of life-threatening or terminal

illness in oneself or a significant other and the recognition of associated losses in the past, present, and future. (p. 4)

The recognition of associated losses that occur throughout life-threatening illness includes the symbolic, physical, and relational/psychosocial losses (Doka, 2002; Martin & Doka, 2000; Rando, 1984, 2000; Roos, 2002). I would suggest that such loss can also occur in serious pediatric illness, which may or may not hold the possibility of death in the future. What the experiences of the families in this research call into question is Rando's (1984, 2000) conceptualization of past and present losses being included under the umbrella of anticipatory mourning. The word anticipate means to "deal with in advance or before the due time, to realize beforehand, to foresee or count upon as certain…to do anything before the appropriate time" (Geddie, 1961, p. 42). Certainly, within the experience of pediatric life-threatening illness there is anticipatory grief and mourning; there is grieving for the possibility of death as well as other experiences of loss at sometime in the future. However, the losses of the present and past have already occurred within the experience of illness. It is important to make some distinctions between grieving the losses of illness which are related to the past and present, from those which have an anticipatory nature, which would include the possibility and fear of death. Given the illness culture of childhood cancer in which the drive to battle the disease is unending, with many viewing death as the ultimate failure, placing the losses of illness within anticipatory mourning may be problematic. Anticipatory grief, as well as the grief related to illness losses, may become disenfranchised, left unattended until death is expected. For one mother in this research, the losses that she experienced and continues

to experience in the context of her daughter's illness, were actually more intense and

painful than what she imagined the actual loss of her child's life would be.

> *Karynn (mother): Well it's the loss of all the things the child could have been,*
> *right? I mean going through...I still go through it. And for her...learning how to*
> *drive, having a boyfriend, graduating school, getting a job...moving into a career.*
> *And...everybody that we know...*[of the] *same age group...they're all married*
> *with kids now...terrible losses... That's more intense than the actual loss of life.*
> *That's far more intense than the actual loss of life...because it's right now, you're*
> *living in it. This is what you've definitely lost...and you're not getting it back.*

Anticipatory Grief in Childhood Cancer: Assisting Family Members to Hold Both
Hope for Life and the Possibility of Death

The Painful Privileging of Loss: Witnessing Coffin Imaginings

One of the foundational aspects of Family Systems Nursing clinical intervention

based on the IBM (Wright & Bell, 2009; Wright et al., 1996) is the uncovering and

distinguishing of illness beliefs within the therapeutic conversation. Within the following

clinical exemplar of Family Systems Nursing practice (transcribed videotape segment of

clinical work from the FNU), the nurse clinician enters a therapeutic conversation with

the parents of one of the research families about their experience of anticipatory grief.

Within this clinical exemplar, which is taken from the third clinical session, the nurse

clinician initiates an inquiry into Isobel (mother) and Marks' (father) beliefs about

prognosis, and the place of illness in their lives. What this nursing inquiry opens up is an

exploration of the anticipatory grief that was a part of these parents' illness suffering.

Within this exemplar, the grief experienced was clearly anticipatory in nature as it

focused on a loss that was anticipated in the future, and it related directly to the

possibility of their son's death.

> Nurse Clinician: Well, it's just interesting that some of the families that we've
> worked with here, and some of the families I've worked with in the past, parents
> who've had a child with cancer...Some people believe that their goal is to cure

the cancer, to completely get rid of it, right? I mean that's not just the hope, that's what they believe can happen. And some other people have a belief around, well "we live alongside of it, or we live with this the best we can, and make a happy life, and do whatever we can within the realities of that." And, I guess I was just wondering about you two, as parents, where you'd see yourself?

In response, both Isobel and Mark shared with the clinician that they were attempting to do both, they were working towards obtaining a cure while simultaneously making the best of the life they had to share together. We can see within this parental response, the ability they had to focus on the present, on engaging in life with their children and each other, despite the knowledge they have that their son Andrew may die.

> Isobel (mother): I think we're doing both…we're trying to make a conscious effort…being aware…just having fun with the kids because we know this could be the last year.

> Mark: And I think that we live right now with the hope that it just stops growing ….*I* eventually hope to see it gone…Cause we know that there's sporadic spots in the rest of his spine, that there is the cell for this tumor. So…to operate on him, to take out one tumor, is fine…but it won't cure it…So, my eventual hope is to find something that makes that MRI…as clear as glass.

> Isobel: Uh-huh, uh-huh…yeah, so we want both.
> Nurse Clinician: It sounds like…you're being realistic in terms of doing what you can now…but not without giving up the hope that there will be…a cure of it.

> Isobel: Yeah, we're making every effort to get rid of it…*completely*. We don't think that's gonna happen in the next MRI, that would be foolish, but also in our mind, we know *he might die* [Mark starts to nod his head up and down slightly; as Isobel is speaking, Mark is looking at her, listening intently]…like, I know in the last week, I spent a lot of time thinking about…his funeral and…

> Mark: Yeah.

> Nurse Clinician: Is that right? And, why did that come up last week?

> Isobel: I think because I got more used to what I was doing with the food…[Mark continues to look at Isobel, listening intently to her words]…not having to make as many phone calls, I had more time to think and I started…I'd picture things, and then I would just try to see it in my head…and I could see him lying in the coffin, I could see myself at the funeral [Isobel begins to cry].

Nurse Clinician: Isobel, I'm curious about that, I mean that's a parent's worst imagining, isn't it? To imagine your child's funeral. And I'm sort of struck with how *painful* that must have been for you, but also how courageous it is [Isobel nods her head when the clinician says the word courageous].

Isobel: Yeah, we've talked a few times that [Mark is looking intently at Isobel and he softly nods his head]…you know…he might die, and what we're going to do after that, if that happens…

Nurse Clinician: Is it helpful, for you to imagine those things or does it discourage you?

Isobel: I don't think it discourages me, more that it makes me a basket case for awhile, and I don't think that helps, but…

Nurse Clinician: But does it…I mean…I guess I'm trying to understand it, cause …some other parents have taught me that every once in awhile, they have to give themselves, this almost painful privilege of imaging the worst case think, they have to sort of indulge themselves in that. It's almost…they have to give into that for a bit…

Mark: Yeah.

Nurse Clinician: …and then they can let go for awhile…is that the way it is for you?

Isobel: Yeah. Well, I don't, I don't fight it. And I imagine it wouldn't work if I did. I just think of it…it just happens and yeah, you get over it…and forget it for awhile.

As the therapeutic conversation progressed, the nurse clinician asked Mark whether he had experienced similar imaginings, and he shared that since diagnosis, he had thought about the possibility of Andrew's death daily. Within this excerpt of videotaped clinical work, the nurse clinician clearly attends to grief that is anticipatory in nature. When Isobel spoke about her coffin imaginings, the nurse clinician did not back away from that conversation, but rather, she opened and extended the conversation, allowing these parents to share some of their worst fears with one another and with the nursing team. In this clinical exemplar, Isobel and Mark were invited to speak what had

been largely unspeakable (Wright & Bell, 2009; Wright et al., 1996) within their experience of illness suffering. Based on her previous research on Family Systems Nursing intervention with the bereaved, Moules (2009c) suggested that one of the clinical practices that is particularly helpful in assisting grieving families has been entering therapeutic conversations in which family members are invited to speak the unspeakable (Moules, 2009c; Wright & Bell, 2009; Wright et al., 1996). She suggested that having the courage to speak the unspeakable with family members, to enter into conversations about death, as well as other sensitive topics "seems to be almost a therapeutic obligation in grief work" (p. 313). What is required in these conversations is not only courage, but also "tenacity, timing, and discernment on the part of the clinician" (p. 313).

In clinical oncology, with the primary focus on fostering family member's hope for a cure, this type of conversation is one that might be viewed as unhealthy or inappropriate given Andrew was not facing close or imminent death. Yet what this conversation opens up is the question of whether we are leaving family members to process the loss and grief they experience as part of illness suffering in silence because of our reluctance as health care professionals to engage in conversations about the possibility of death. If we return to a consideration of the mythic tale of Persephone and Demeter, this conversation may represent the times when family members enter the world of Hades, moving towards what Stroebe and Schut (1999, 2001, 2010) have identified as a loss orientation to face the real possibility that one day their child may die.

Anticipatory Grief: Leaving and Returning

The nurse clinical who worked with this family, articulated her beliefs about anticipatory grief in the research interview that we shared:

Nurse Clinician: *I think* anticipatory grief is learning about letting go…learning how to let go and say good-bye to someone. And that post-mortem grief is about finding connection.

Letting go is part of the process of leaving another who we love and feel attached to. Throughout various conceptualizations of anticipatory mourning, theorists have considered the role of rehearsing death in anticipatory grief and mourning (Fulton & Fulton, 1971, Rando, 2000). Were these parents learning how to let go of their child by rehearsing his death? Was this a preparation for the possibility that Andrew might die one day? And how many other parents rehearse the death of their children, in a silent, unacknowledged way because it is too painful to verbalize these thoughts and possibilities? Might we as nurses have played a role in silencing such imaginings by our inability to enter therapeutic illness conversations about illness suffering?

For Gadamer (1989) the hermeneutic experience is about venturing out into something that is alien to yourself, and in that venturing, coming to know something different about lifeworld and yourself. In this venturing out, one comes to know something in such a way that with the return to yourself, you are no longer the same, you return to yourself in a different way. What has been learned in the process of alienation, what one comes to know, to understand differently, is cultivated in memory, and it is in the remembering that one comes to think and live differently. Entering this new place of knowing also has to do with being in touch with something, with making something tangible. This venturing out, alienation, and return has been described as a movement back and forth, and it is this very movement which is central to hermeneutics (D. W. Jardine, personal communication, May 2008). "To recognize one's own in the alien, to become at home in it, is the basic movement of spirit, whose being consists only in

returning to itself from what is other" (Gadamer, 1989, p. 14). In reading Gadamer's words once more, I am called to consider how the experience of anticipatory grief is very much a hermeneutical experience: venturing out, experiencing the alien, and experiencing that which is other, is then followed by a return. Just as in the mythic tale of Persephone and Demeter, these parents repeatedly ventured into the unknown by imagining themselves at their child's funeral, after which there was a return to life. Rather than being solely about letting go, saying good-bye, or leaving, this research suggests that anticipatory grief in the context of a pediatric illness which may or may not end in death, is about an ongoing journey into the unknown, it is a process of leaving, finding oneself in that which is other, and then returning to life.

This rhythmic movement between leaving, alienation, and return is also reflected in Stroebe and Schut's (1999; 2001) conceptualization of grief, which was described earlier in this chapter. Within anticipatory grief, the loss orientation is similar to the process of leaving; in the clinical exemplar presented, the leaving and alienation shows itself in Isobel and Mark's coffin imaginings. The life restoration orientation, or return, is reflected in Isobel and Mark's commitment to hold the hope for a cure in the future, and their attempts to make the most of each day despite the knowledge they have that their son may die in the near future.

Illness Survivor Grief

The parents within this research experienced profound grief once their child's treatment for cancer had ended. This was surprising to me, I would have expected the time of survivorship to be characterized by a relief of illness suffering. However, for all of the families within this research study, the transition to life after treatment brought

new challenges and experiences of grief. What partly was lost for these parents in the course of cancer treatment was their purpose and identity outside of being the parent of an ill child. In many ways, their lives had been consumed in fighting for the lives of their children, and in that fight they seemed to have lost who they were. Further, some of the losses that parents had experienced within the illness experience were not grieved until they had reached the end of treatment. In disenfranchised grief (Doka, 1989, 2002), the social and cultural communities that families are a part of do not recognize, acknowledge, or support family members in their grief (Doka, 2002). Within these parents' experiences of survivor grief, not only was their grief not acknowledged or supported, but the social and cultural communities they were a part of expected them to be celebrating, grateful, and joyful, which worked to intensify their experiences of loss and grief during their transition into the time of survivorship.

> *Isobel (mother): I was running, running, running…I was on adrenaline…that's when I really realized…when his tumors were gone. I was depressed for eight months. The doctor said, "the tumor's all gone, there's not activity there…go live your life, and be happy." We couldn't even be happy…it was weird, it was a very strange feeling…and I remember, I had to do some more EMDR after that because I was having…post-traumatic stress, where you start to feel…because you couldn't feel while you were too busy, right?...it was just a weird crash.*

> *Interviewer: So, it was at the point when the said, "there's no activity...?"*

> *Isobel: Yeah! It started right after I had to stop praying. And…I remember… here's a question I did ask… "who am I?" And I remember saying to myself, "I'm not just a cancer fighting woman…" And it had become my identity…it suddenly came to a stop, and I remember counting…how many things I had to do in a day …cause he was on the IV treatment…and so, suddenly…I had eighteen things to do a day that suddenly were gone…and instead of being relieved and overjoyed, I felt empty and it's like, "what do I do now?"*

> *Interviewer: Is that a sense in some way that…the purpose that you had in your life, from doing all those things, was suddenly gone?*

> *Isobel: I think so…cause that's the only purpose I'd given myself for so long…I*

couldn't be anything else...and I had to figure that out...and it took some time, just time to...I guess kind of grieve...to grieve...not losing all that work, but grieve...the suffering that I never grieved while we were in it, I remember crying a lot …so after the tumor was gone...like, now I have to grieve all that other junk...and I didn't have any way of doing it, and people you know, don't understand...well, the thing is you feel pretty isolated because people don't know how you feel. And I remember talking with Mark about it...I didn't know how he felt, and he didn't know how I felt, cause our roles were still different, even though we were both parents...

For Karryn (mother), the long haul of her daughter's illness brought intense suffering for her as well as other family members, and led to her experiencing a significant clinical depression. Karynn and her daughter Lauren had visited the FNU multiple times over a period of ten years. The focus of the last set of clinical sessions at the FNU had been the suffering that Karynn experienced in relation to the ongoing, complicated illness experience that she and her daughter continued to live after cancer treatment. Similar to Isobel, Karynn's anger and emotional fight had sustained her throughout Lauren's initial cancer treatment, but in facing the multiple chronic medical complications which were long-term side effects of Lauren's chemotherapy and radiation treatment, Karynn experienced a profound and unrelenting suffering. During one of the therapeutic conversations with nurses at the FNU, a nurse clinician acknowledged the suffering that Karynn was experiencing, and inquired about what had been the most difficult part of her illness experience:

> Nurse Clinician: The team and I want to really acknowledge what you've been through…and the amount of suffering that you've experienced within your family. What's been the most awful part, of all the experiences you have gone through in the last few years?

In response, Karynn, speaking very slowly and through her tears, described her illness suffering in the following manner:

> Karynn (mother): It just seems never ending…I'm just really tired, I never feel

like myself, I'm perpetually in a state of flux, I don't feel like I have stable footing, ever. She was a really, really good girl, and I was an honor student, and I got into university, and I was doing it all by myself…and I had vision and determination…I've lost it. It's like I've lost me…I can't seem to get back on the road…And I was doing everything I could to be a good mother…and then it was just like the stops on the way to Disneyland got bigger…then we were taking detours, taking back roads…next thing you know there isn't a road to drive on anymore, to get to where I want to go. It's like I'm stuck in the mire now…I'm in the muck. I'm stuck, I can't get out…Thank God I have a little girl now, or I probably would be dead, to be honest. I don't think I'd be able to stay alive. I think I'd either be in the hospital, or I would have committed suicide. That's how depressed I've been…I didn't even feel like having Lauren was enough to keep me alive anymore…before it used to be, "as long as she's alive, I'll be okay…if she dies, then I'm in trouble." But, then it just got to the point where I couldn't even cope with her being alive anymore…last year was really bad, and then after she got better…then I fell apart.

Within the IBM (Wright & Bell, 2009; Wright et al., 1996), nurses are guided by some specific beliefs about families and illness. One of those beliefs is that "problems do not reside within individuals but between persons in language" (p. 48). Claiming the belief that problems are drawn forth in language can have a powerful influence within clinical nursing practice. This belief about the centrality of language is also reflected by Gadamer (1989) in his articulation of a philosophy of hermeneutics. Naming something is understood as invoking something, in naming there is a process of invocation. Naming something, calls something, invokes it forward (D. W. Jardine, personal communication, April 3, 2008).

.… "proper name" – i.e., the name by which something is called…a name is what

it is because it is what someone is called and what he answers to. It belongs to the

bearer. The rightness of the name is confirmed by the fact that someone answers

to it. Thus it seems to belong to his being. (Gadamer, 1989, p. 405)

When Karynn participated in clinical intervention based on the IBM (Wright &

Bell, 2009; Wright et al., 1996), the nursing team offered her an idea which led to a

lessening of her illness suffering. Karynn was asked whether it might be helpful for her to

use the word grief rather than depression to describe her experiences of sadness,

irritability, and struggle (videotaped clinical segment):

> Nurse Clinician: The words that you're...what depression feels like…I'm just curious about…what would happen, or would it be even possible to use…another word to describe it. And I'm wondering if something like grief would fit for you?

> Karynn: Well, that would be a relief to use that word…sometimes when I get upset, and people are like…"why are you upset?" Well…"I'm still grieving." I'm constantly grieving Lauren, every time she's supposed to hit another milestone [crying]…have boyfriends, get married, have kids, graduate from high school…I grieve all that. But, I guess I don't…characterize my everyday as …"this is grief." I characterize it as depression…so it makes me want to cry.

> Nurse Clinician: What would be different…if you viewed what you're feeling, …experiencing, as grief rather than depression?

> Karynn: Everything, really. Just, even using the word makes me…I don't know, it kind of hits, it hits me in a way that makes me just feel, instead of feeling low, it just makes me feel like crying. It's strange actually…you just bringing up a different word for how I feel everyday…just makes me want to cry.

What was invoked in this interventional offering was a different name for her illness

suffering, a name that for Karryn, invoked something very different than the word

depression. Grief belonged to her being, and made it possible for her to believe

something different about the suffering she was experiencing. During our first research

interview, Karynn shared with me what it had meant to have the nursing team at the FNU

offer her the idea that her suffering might be described as grief rather than depression.

For Karynn, changing the language about her illness suffering from depression to grief

had a profound and enduring impact.

> *Karynn (Research Interview): Changing a term, saying "maybe this is actually grief that you're…experiencing…"…I was hearing in my own voice…that sadness …but also a sense of relief that someone was actually acknowledging the pain* [Karynn begins to cry]. *When…you slowly watch someone's life…it's like a spiral downwards…and it hurts… And the people that are around you…you don't get*

that acknowledgement of pain...the grief you're going through...People need to have that...you need to be allowed to be angry, to be...sad, to be disappointed...because things have changed, and they're never going to come back. I think parents really need to have...an opportunity...to be in pain, and for people to say "I recognize this as your pain." And to embrace them in that...allow them to be there...If that had happened more for me...it wouldn't have been drawn out for so long.

Later in the research interview, I also showed Karynn a videotaped segment of part of the reflecting team offered to her by the nursing team at the FNU during that same clinical session. A reflecting team is a specific therapeutic approach in which the nursing team acknowledges individual/family suffering, and offers their ideas, as well as commendations to a family. After the nurses have observed the therapeutic conversation between the nurse clinician and family behind a one-way mirror, the family is invited to move behind the one-way mirror together to listen to the ideas and impressions of the nursing team (Wright & Bell, 2009; Wright et al., 1996). Within this videotaped segment, the nursing team expanded their ideas about using the word grief to describe Karynn's suffering. One nurse offered Karynn the idea that grief is a profound spiritual experience as well as an emotional one:

> Joanne: I'm trying to think about the ways that thinking about what she's experiencing as grief rather depression might serve her...I wonder of some of our ideas around grief might be helpful...What we've come to believe here, in our work, and some of our research...is that we don't see grief as just an emotional experience...we see it as a profound spiritual experience...in people who have had somebody die...the work of grief is about finding ways to stay connected to this person who isn't physically present in your life anymore...it's about continuing a relationship...and that work is spiritual work in lots of ways. And I was wondering about that very idea...in terms of her experience of losses around Lauren's illness, I was wondering if that idea would be helpful to her...If she were to embrace this as grief that's she's going through, how then does she say hello to a new and changed relationship with the dream that didn't come out the way it was supposed to? With a child who is different than she was supposed to be? With a road that doesn't end up in Disneyland?...To think of it in this way... gives permission to absolutely grieve what you wanted to be...and to absolutely feel intense and profound sadness around that, and to question why it happened...

and to not like it. But also, that we know now in our work around grief, that it's also about being able to continue to live forward in the midst of that sadness, and to say, "okay, things are different, now we form a new relationship." Even a new relationship with our hope…

After viewing the videotape of the reflecting team in our research interview, Karynn described the difference it had made to name her suffering grief:

> *Karynn: When I'm depressed, I have absolutely no control. And when I have grief, I have more control. And, part of it, is around responsibility versus no responsibility. So with depression, I feel like I have more responsibility. It's my…error; Somehow, I have…created the depression… through my own doing. Whereas grief, is something beyond my control, I didn't have any control over her illness. So it lets me off the hook a little bit, because for me, the one term that isn't being used at all in here…which has been the ongoing problem for me…is guilt. And parental guilt, survivor guilt, all this kind of thing…just really plays into my experience…the guilt has been…tremendous...so, when I said, "oh, what a relief,"… it lets out some of the guilt, it lets me off the hook, so to speak.*

These therapeutic offerings were then further explored with Karynn through the offering of a therapeutic letter and a research article (Moules et al., 2004), which were sent to her home after the clinical session was completed (see Appendix H). For this mother, the act of naming her suffering grief within the therapeutic conversation with the nurse clinician, during the reflecting team, and then again in a therapeutic letter, brought a profound change in her understanding of and beliefs about her suffering. No longer did she feel the same weight of responsibility and guilt within her experience of parental illness suffering.

Concluding Thoughts

What this research draws attention to is a need to attend to the grief of losses that occur within illness, as well as the anticipatory and illness survivor grief experienced by family members in the context of living with childhood cancer. For the families who participated in this research, experiences of loss and grief were an integral part of their

illness suffering. Family members experience grief responses which are very similar to responses reported by the bereaved following the death of a loved one. These included cognitive, physical, emotional, and spiritual responses to loss. At the time of diagnosis, parents report entering a state of shock that is characterized with profound disbelief. The entrance of childhood cancer brings a loss of safety and security, and a profound loss of control for both parents and children. Compounding these loss experiences, were complex relational and symbolic losses which led to relational disconnection, isolation, and silence between family members.

In addition to the illness losses experienced with the family unit, at times family members grieved the death of fellow cancer patients. These experiences also initiated experiences of anticipatory grief, inviting parents to ask the following internalized questions: "when will it be my turn? Will my child die?" I have argued that within pediatric oncology there is a need to carefully articulate the difference between the illness losses that have already occurred within the past and present from those which have an anticipatory character. There is a risk that experiences of loss may become disenfranchised if they are considered together under the conceptualization of anticipatory grief within illness, as previously articulated in the work of Therese Rando (1984, 2000).

Within clinical exemplars of family intervention at the FNU, I explored how nurse clinicians worked to explicitly attend to the illness grief of family members living with childhood cancer. In one of the clinical exemplars presented, a nurse clinician carefully supported and guided a mother and father through the process of "speaking the unspeakable" (Wright & Bell, 2009, p. 188, 189): they were given an opportunity to share

the fears they had about their child's possible death, as well as their imaginings of being at their son's funeral, and seeing him laying in a coffin. In parental experiences of anticipatory grief, there was evidence of a movement back and forth between an orientation of loss/grief, and an orientation focused on engaging in family life, new life, and hope for the future. Prior to doing this research on illness suffering in childhood cancer, I believed that what families might most need is more assistance in entering the difficult conversations about fears related to the possibility of death. What I have learnt in the process of asking these research questions, is how important it is for nurses to support and assist family members to hold hope and engagement with life, while sensitively offering them opportunities to claim and explore their experiences of loss and grief within illness suffering.

I suggested that the DPM (Stroebe & Schut, 1999, 2001) is one contemporary bereavement model that might be helpful for understanding and conceptualizing experiences of loss and grief within pediatric life-threatening illness. Based on the family experiences of illness grief described in this research, I have suggested that the loss orientation within the DPM be modified for use in pediatric life-threatening illness. The loss orientation would need to focus on processing the many different losses discussed within this chapter. Within pediatric life-threatening illness, and within clinical intervention with families in this research study, the focus was not on processing a death, but rather, on processing the losses which were a part of having a child diagnosed and treated for a life-threatening illness such as cancer. These included the loss of family normalcy and the sense of being at home in the world (see chapter six), physical, relational/psychosocial, and symbolic losses (Doka, 1989, 2002; Martin & Doka, 2000;

Rando, 1984, 2000; Roos, 2002), as well as anticipatory (Rando, 1984, 2000) and illness

survivor grief.

Within the next chapter, I will explore what families found most helpful about the

clinical intervention they participated in at the FNU. There I will further articulate how

Family Systems Nursing intervention based on the IBM (Wright & Bell, 2009; Wright et

al., 1996) helped nurses to attend to the illness suffering experienced by families in the

context of childhood cancer.

CHAPTER NINE: A JOURNEY INSIDE FAMILY INTERVENTION

In the Storm

Some black ducks
were shrugging up
on the shore.
It was snowing

hard, from the east,
and the sea
was in disorder.
Then some sanderlings,

five inches long
with beaks like wire,
flew in,
snowflakes on their backs,

and settled
in a row
behind the ducks –
whose backs were also

covered with snow –
so close
they were all but touching,
they were all but under

the roof of the ducks' tails,
so the wind, pretty much,
blew over them.
They stayed that way, motionless,

for maybe an hour,
then the sanderlings,
each a handful of feathers,
shifted, and were blown away

out over the water
which was still raging.
But, somehow,
they came back

and again the ducks,
like a feathered hedge,

let them crouch there, and live.

If someone you didn't know
told you this,
as I am telling you this,
would you believe it?

Belief isn't always easy,
but this much I have learned –
if not enough else –
to live with my eyes open.

I know what everyone wants
is a miracle.
This wasn't a miracle.
Unless, of course, kindness –

as now and again
some rare person has suggested –
is a miracle.
As surely it is.
(Oliver, 2006, pp. 62-64[3])

I begin the writing of this third analysis chapter, the chapter which will focus on

what families found helpful about their participation in therapeutic conversations (Bell &

Wright, 2011; Wright & Bell, 2009; Wright et al., 1996) with nurses at the FNU, with

this poem by Mary Oliver. I do this because just as these sanderlings found themselves in

the midst of a raging winter storm, and so these families found themselves in a storm,

facets of their family life, a life which they had known and loved, fell apart in the face of

their child's life-threatening illness. What did they need in the face of deep individual,

relational, emotional, and spiritual suffering? In part, they needed and received moments

of shelter, protection, and safety from the storm that raged around them. Yet, just as Mary

Oliver hints in her words "belief isn't always easy" (Oliver, 2006, p.63), family members

[3]From *Thirst: Poems by Mary Oliver* (pp. 62-64), Boston, MA: Beacon Press. Reprinted with permission.

also spoke of how entering therapeutic conversations about their illness suffering and their beliefs about illness, although very helpful, was also painful, awkward, and even embarrassing. Caputo (1987) has suggested that

> in the thin membranes of structure which we stretch across the flux in the thin fabric we weave over it, there are certain spots where the surface wears through and acquires a transparency which exposes the flux beneath. There are certain breaking points, let us say, in the habits and practices, the works and days, of our mundane existence where the flux is exposed, where the whole trembles and the play irrupts. Then we know we are in trouble. The abyss, the play, the uncanny - in short, hell – breaks loose, and the card castles of everydayness come tumbling breaks loose, and the card castles of everydayness come tumbling down. Something breaks through because the constraints we impose upon things break down. (pp. 269-270)

These words speak to the experience of families who live with the presence of childhood cancer in family life. The flux, the abyss, hell itself breaking loose, leaving the everydayness of family life without the meaning it once held, leaving family members in a place of searching for a sense of being at home in human life, leaving each of their relationships profoundly altered. For Caputo (1987), "radical hermeneutics arises only at the point of breakdown and loss of meaning, the withdrawal and dissemination of meaning – in short, the thunderstorm" (p. 271). For him, the role, the very calling of a radical hermeneutic is

> to make an occasional excursion into that desert. It exposes itself to the twilight world of ambiguous and undecidable figures which populate that shadowy sphere.

Its role is not so much to "come to grips" with it – that is the metaphysics of grasping, and we have insisted on its ability to elude our grip – as it is to cope with it or, best of all, to stay in play with it. (1987, p., 271)

What this research presents is an interpretation of how nurses may intervene to assist families in coming to cope with the flux, the abyss, with illness suffering. Somewhat of a paradox arises here, for in order to learn how to live with the flux, to venture into the midst of suffering, families need protection, safety from the storm that swirls around them, even if that safety is temporary and time-limited in the context of family intervention. As the sanderlings nestled under the shelter of the wings of these black ducks, families need refuge from the storm so that they can venture into the desert of illness suffering. This does not mean that the storm is quieted, that we place a metaphysical grip upon it, quieting and soothing the raging, but that we assist family members to find shelter from it, allowing them a space within the context of relationship to reflect upon what Gadamer (1989) might call interruption, or for Caputo (1987), the very opening, and break down of human life. As nurses, it may be that part of our role is to provide safety, a space set apart, and then to venture with family members into the midst of the flux. What this venturing will ask is that we be open to the address of the other, entering into a relation of moral obligation to the other, a relation that has the nature not of professional distance, hierarchical expertise, and detachment, but one marked by understanding, witness, dialogue, friendship, kindness, and even love.

The Creation of a Liminal Space for Healing: A Safe Place for Conversation and the Sharing of Illness Suffering

Within family intervention based on the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996), nurses are guided to carefully create a context for

changing illness beliefs. This is done, in part, through the careful cultivation of a collaborative relationship between the nurse and family. Wright and Bell (2009) suggested that the creation of the therapeutic relationship is often a taken-for-granted process that begins in the first few moments of meeting with a family. This relational work is conceptualized as a process that needs to be continually attended to, strengthened, and renewed throughout the course of the clinical work. The development of a collaborative relationship with multiple family members, as well as the family as a unit should be considered an intervention practice rather than a prelude to later entering the interventional phases of therapeutic work with a family.

Within the IBM, the collaborative nurse-family relationship is cultivated in part through the following "rituals of welcome": greeting the family by introducing oneself, offering a handshake, using eye contact/facial expressions to convey interest, explaining the setting and nature of the work, offering a plan for the therapeutic conversation/clinical session, and offering parameters for the duration and scope of the therapeutic relationship (Wright & Bell, 2009, p. 146). Similar to previous research on this clinical approach, families in this research highly valued the "family environment" at the FNU, and the careful attention to relationship. The process of relational engagement sometimes began even before the family met members of the nursing team:

> *Ben(father): From the moment we walked in, from the gal that received us…she met us with a gracious welcome...* "oh here, let me get you some water." *And I thought,* "wow, this is a little different than…last time" [referring to the family's hospital experience]… "let's get down to business, this is serious…your son's dying, we've got to get this cancer therapy going"…*And so you automatically felt...then Lisa* [nurse clinician] *came in and introduced herself...*

The clinical work with this family had concluded four years prior to my research interviews with them, but these moments of introduction, and their relational impact had

remained with them many years later. These moments were the beginning of providing a

refuge, a safe space for a therapeutic conversation about illness suffering. This safety was

created not only through conversation, and non-verbal behaviors, but also by the physical

environment that families entered:

> Ben (father): Here it was relaxed…you come in, and there was no threat…no
> environmental, kind of, hospitalizing kind of thing…You came in, and we sat
> down, and everybody got a chance to talk.

The actual physical space and the positioning of family members in a circle, with the

nurse sitting alongside family members within that circle also impacted the therapeutic

relationship, the relational space that was created. This experience differed remarkably

from some of the interactions experienced by family members in the hospital.

> Ben (father): None of that happened at the Children's…the very first person I
> knew, was Dr. Miller, and I thought he was on my side. He's sitting on the other
> side of the table [in reference to a family meeting in which the health care team
> spoke to both parents about Cameron's diagnosis]…lined up with all these
> "people." It's an oppositional setting…

Later in this research interview, these parents explained further how important it had been

for them to sit in the circle at the FNU:

> Interviewer: So, the circle…when you talked about wanting to position yourself
> differently [in reference to the meeting at the hospital]…was there something
> about sitting in a circle that even helped you?
>
> Ben: Yeah…and that's so true. And I think the size of the circle was important. At
> the Children's we were…oppositional. A long line of tables…like three or four
> tables…so they were all lined up on that side, and there's just two of us on this
> side. Where…at the [FNU]…it was like in your living room in a sense…
>
> Jan: But the table…like the table was littler too...so you were in closer proximity
> in a lot of ways…to one another.

As I did this research interview, I found myself intrigued by the impact that sitting

in a circle had had on this family, a circle where the family was invited to feel like they

had entered a living room rather than a clinical environment. The symbol of the circle or sphere has lived within and influenced human life for centuries. Jung and his colleagues (1964) explored the meaning of this sacred symbol:

> The circle (or sphere)…expresses the totality of the psyche in all its aspects, including the relationship between man and the whole of nature. Whether the symbol of the circle appears in primitive sun worship or modern religion, in myths or dreams, in the mandalas drawn by Tibetan monks, in the ground plan of cities, or in the spherical concepts of early astronomers, it always points to the single most vital aspect of life – its ultimate wholeness. (Jung, von Franz, Henderson, Jacobi, & Jaffé, 1964, p. 266)

These authors go on to explain that the architecture of the mandala has played a pivotal role in the ground plans of both "secular and sacred buildings in nearly all civilizations; it enters into classical, medieval, and even modern town planning" (p. 269). To further explore the embedded and invisible influence of the circle Jung et al. (1964) described Plutarch's account of the building of Rome:

> According to Plutarch, Romulus sent for builders from Eturia who instructed him by sacred usages and written rules about all the ceremonies to be observed – in the same way "as in the mysteries." First they dug a round pit…and into this pit they threw symbolic offerings of the fruits of the earth. Then each man took a small piece of earth of the land from which he came, and these were all thrown into the pit together. The pit was given the name of *mundus* (which also meant the cosmos). Round it Romulus drew the boundary of the city in a circle…The city founded in this solemn ceremony was circular in shape. (Jung et al., 1964, p. 269)

The theory of the mandala was involved in the creation of Rome, and the centre of the

city, otherwise known as the *mundus,* "established the city's relationships to the "other"

realm, the abode of the ancestral spirits (the mundus was covered with a great stone,

called the "soul stone." On certain days the stone was removed, and then, it was said, the

spirits of the dead rose from the shaft)" (p. 272). The mandala ground plan was never

guided by economic or aesthetic motivations, rather by, "a transformation of the city

into…a sacred place bound by its center to the world" (p. 272). In this way the very city,

as well as fortresses and temples, became symbols of psychic wholeness, creating a

specific influence on the human being who entered or lived in that place (p. 272).

Isobel, another parent in this research, similarly described the relational safety

that was created for her family at the FNU. She related her experience of safety to the

boundary that was placed around the therapeutic conversations. Isobel used a metaphor to

express what she meant by this: for her, this safety, or boundary, was like the difference

between a fire burning in a fire pit versus a fire left to burn in an open field. Interestingly,

here too, the image of a circle emerges. Most fire pits are circular in nature, providing a

physical boundary for containing, or enclosing a fire. If we imagine the fire burning in an

open field, it is possible to imagine how such a fire might spread wildly, burning out of

control, and leaving much damage along the path that it travels.

The words and experiences of these families, as well as the ancient lineage the

circle holds, led me to consider the relationship and the safety created for families as a

physical, emotional, and spiritual space or boundary where it became possible for illness

suffering to be called forward, experienced, and shared. In the calling forward of

suffering there was the physical, circular boundary in which to hold it, containing it as it was presented.

This therapeutic relational space or boundary might also be considered a liminal space (Turner, 1982). Arnold van Gennep (1960), a French sociologist wrote *Rites de Passage,* which was first published in 1908. From this work, the term rite of passage came to be used in the context of life crisis rituals (Turner, 1982). Van Gennep articulated three distinct phases present in any rite of passage: separation, transition, and incorporation. Victor Turner (1982), an anthropologist, in his discussion of the liminal as part of play, flow, and ritual described the separation and transition involved in a rite of passage:

> The first phase of *separation* clearly demarcates sacred space and time from profane or secular space and time…During the intervening phase of *transition,* called by van Gennep "margin" or "limen" (meaning "threshold" in Latin), the ritual subjects pass through a period and area of ambiguity a sort of social limbo which has few…of the attributes of either the preceding or subsequent profane social statuses or cultural states. (p. 24)

Initiands who are in the process of passing through this threshold, a liminal or transitional space, "are associated with such general oppositions as life and death…they are at once dying from or dead to their former status and life, and being born and growing into new ones" (Turner, 1982, p. 26). Stephen Levine, a social scientist and expressive arts therapist, drew on the work of van Gennep (1960), Victor Turner (1982), and the history of gift exchange (Hyde, 1983; Mauss, 1967) to describe how his students in the arts and psychotherapy are led through a rite of passage, a ritual process, in which they

experience a transformation into becoming a healing artist (Levine, 1997). In the reading of his work, I was drawn to consider how this ritual process shared a striking kinship to the one that families engaged in as they explored their illness suffering with nurses at the FNU. In his reading of Turner (1974), Levine described the liminal space that these expressive therapists enter:

> Liminality is a position of structural outsiderhood and inferiority. To be liminal is to be vulnerable…At the same time, liminality implies potency, the capacity to become more than one has been. The liminal person is "naked," as it were; he or she is without defenses yet has what Turner calls "the powers of the weak" (Turner, 1974, p. 95)…Liminality need not imply isolation…not only the individual but others, sometimes even the whole community, pass into a liminal stage. In such a condition, they stand before each other divested of the masks emblematic of their social status. They meet not as a series of individual "I"s but as an "essential We," a community characterized by the feeling of "humankindness." Turner calls this social condition, "communitas." The ritual process introduces communitas into the structure life of a group; it breaks down norms in order to renew and regenerate…life. (Levine, 1997, p. 49, 50)

The physical, emotional, and spiritual space or boundary that the families in this research described, could similarly be understood as the movement of nurse and family into a liminal space, into communitas and an experience of humankindness. This liminal space was a place where masks were divested, and within a spirit of communitas, suffering could be called forward, to become present within the circle of nurse and family.

To Bear Witness and Give Testimony to Suffering: Possibilities for the Sharing of Illness Suffering

The first research family was a large family who had come to the FNU for a total of six clinical sessions. After the first two sessions with nine family members, the clinical work evolved into a focus on the marital system. Despite being present at only two clinical sessions, the two youngest siblings in this family, Lizzie (14 years) and Jason (12 years) were eager to come and participate in a research interview. During the first research interview, Lizzie and Jason spoke very openly about how difficult the experience of cancer had been for them, and the profound influence it had had on their relationships with other family members. Earlier, in chapter six of this thesis, I described these children's experiences of feeling excluded from the family, and their sense that they had actually lost their parents for the period of time that Cameron was receiving cancer treatment. One of the internalized questions that Jason had asked himself during Cameron's illness was whether his parents still loved him, given that they spent so little time with him.

As the children shared their experiences, Ben (father) and Jan (mother) sat listening intently to their children's stories. It was only in this research interview that Ben and Jan became more fully aware of the illness suffering experienced by their younger children. While the children spoke directly to me, both parents sat back, in what appeared to be a place of deep reflection, listening quietly and intently to what their children were saying. Ben later expressed how surprised he had been, stating that this had been the first time he had heard his children express these difficult experiences and emotions.

> *Ben: Just listening today…they were experiencing a tsunami of their own, that they couldn't comprehend…"I never saw mom and dad," "I never got to see Cameron," "I didn't understand what the term better meant"…I'm hearing that*

for the first time now…four years later!…that's why I was so quiet…

Following this first research interview, I spoke on the phone with Ben, and he shared that after the research interview he had noticed a change in the family dynamics; both he and Jan had experienced an enhanced connection with Lizzie and Jason. He associated this change with the opportunity the family had had to hear one another's experiences with illness in our research interview. Ben believed that in listening to one another within the research interview, they had come to understand each other's experiences differently. He felt quite strongly that what had been so helpful was to have someone else asking the questions of the children. Somehow, having me as the researcher sitting with them, asking the children what their experiences had been, gave the parents the opportunity to sit back, and listen differently. It helped the parents to take a more passive role, freeing them up to listen and understand their children's experiences differently.

What is important here is not so much that the family found the research interview to be therapeutic, but the observation I had made of the specific behavioral interaction that occurred within that research interview. In our final research interview, Ben and Jan explained that this experience of hearing one another differently, having the chance to sit back and listen to one another's illness experiences, had also happened in the clinical work at the FNU, and that this had been one of the aspects of the process of clinical intervention that had been extremely helpful to them as a family.

> *Ben: The beauty of the FNU was…you had a neutral person there who was able to draw out things from all of us…and that happened here when we had the first research interview with the kids here…It opened my eyes…it opened their eyes… we had a talk about it at home, that day. And they found it very helpful.*

Repeatedly, these parents spoke of how valuable it had been to have the presence of the nurse clinician [at the FNU] who acted as a "neutral, third party person," and through the unique questions that the nurse asked, they felt what was drawn out was each family member's experience with illness. Having the opportunity to sit and listen to one another's stories of illness at the FNU had been very helpful to them as a family. In his interpretation of Gadamer's philosophical hermeneutics, Grondin (1994) noted that it is "only in conversation, only in the confrontation with another's thought that could also come to dwell within us, [that we] can we hope to get beyond the limits of our present horizon" (p. 124). Within the process of being invited into a therapeutic illness conversation, these family members were given an opportunity to hear one another's experiences of illness suffering, and as these thoughts came to dwell in the lives of other family members, they created an opportunity for family members to move beyond the limits of their present horizon of illness suffering. In being given the opportunity to listen to one another differently, their own suffering was opened to the possibility of change and transformation.

As I moved on to conduct research interviews with other families and nurse clinicians, I observed a similar interaction between family members and nurse clinicians on the videotapes of clinical intervention with other families. For example, I observed what I will call a 'witnessing of suffering' in the videotaped segment that I presented in the last chapter where Mark and Isobel spoke with the nurse clinician about imagining themselves at their son's funeral, and seeing him lying in the coffin. Here, I will revisit that specific section of the therapeutic illness conversation:

Isobel: I know in the last week, I spent a lot of time thinking about...his funeral…

Mark: Yeah.

Nurse Clinician: Is that right? And, why did that come up last week?

Isobel: I think because I got more used to what I was doing with the food…[Mark continues to look at Isobel, listening intently to her words]…not having to make as many phone calls, I had more time to think and I started…I'd picture things, and then I would just try to see it in my head…and I could see him lying in the coffin, I could see myself at the funeral [Isobel begins to cry].

Nurse Clinician: Isobel, I'm curious about that, I mean that's a parent's worst imagining, isn't it? To imagine your child's funeral. And I'm sort of struck with how *painful* that must have been for you, but also how courageous it is [Isobel nods her head when the clinician says the word courageous].

Isobel: Yeah, we've talked a few times that [Mark is looking intently at Isobel and he softly nods his head]…you know…he might die, and what we're going to do after that, if that happens…

Nurse Clinician: Is it helpful, for you to imagine those things or does it discourage you?

Isobel: I don't think it discourages me, more that it makes me a basket case for awhile, and I don't think that helps, but…

Nurse Clinician: But does it…I mean…I guess I'm trying to understand it, cause …some other parents have taught me that every once in awhile, they have to give themselves, this almost painful privilege of imaging the worst case think, they have to sort of indulge themselves in that. It's almost…they have to give into that for a bit…

Mark: Yeah.

Nurse Clinician: …and then they can let go for awhile…is that the way it is for you?

Isobel: Yeah. Well, I don't, I don't fight it. And I imagine it wouldn't work if I did. I just think of it…it just happens and yeah, you get over it…and forget it for awhile.

As the nurse engaged intently in conversation with one parent, the other parent appeared to watch and listen intently as their partner answered the questions of the clinician. I had begun to wonder about the therapeutic impact of family members bearing witness to the

illness testimonies of other members of the family within the process of a therapeutic

conversation. Each family member sat listening to the intense suffering of the other, and

it seemed important that the family member sharing their illness testimony was speaking

to the nurse, the nurse who could act to hold and contain the suffering. Within these

testimonies, were found experiences that may have been too painful to openly share with

each other, but the nurse's presence allowed family members to witness one another's

suffering, learning about the internal conversations that other family members are having

with themselves in the midst of their illness suffering.

When I interviewed the nurse clinician who had worked with Mark and Isobel, I

explored this with her, wanting to understand better what her experience had been of that

therapeutic conversation with Mark and Isobel.

> *Interviewer: In that videotape…he's talking for a long time, and the video is of her…she's not saying anything…but for a long time they just videotaped her…and he's talking in the background. And she's looking at him quite intensely…and listening quite intensely…or that's my perception of it…so do you think there's something about you being the clinician present in the room…he's talking, he's giving his answer to you, right?*

> *Nurse Clinician: …and she gets to be a witness to it…Well, I mean, if you...look at Lorraine Thirsk's analysis of the three grief conversations* [a recent qualitative analysis of family intervention at the FNU based on the IBM]…*the mother is able to hear her kids say that she was an available mother…they had said that to her many times before, but she was able to hear it that time. And so in the next session…she was at a lot more peace around that…I explored with her…why it was that she was able to hear it this time…and her response was…maybe because it's not me holding this all together in here. But you're holding it all together and that frees me up to hear, and listen differently…Which would fit with this one as well…that as he's talking to me directly, she's able to almost have that… phenomenologically reflective stance, where she's able to sit back and hear differently. When you're not in it…she's just witnessing it…*

Later in that research interview, the nurse clinician reflected on how the witnessing of

one another family member's experience of illness, witnessing of one another's suffering,

is only possible when the clinical work is focused on the family, rather than an individual

family member:

> *Nurse Clinician: Which is…speaks to why* [emphasis]…*you need to do this work in families, right…not individuals. You don't get a chance to witness…*

Certainly the listening to, and witnessing of illness stories, stories of suffering as

well as hope, joy, and strength has been a well documented and researched aspect of

clinical work based on the IBM (Duhamel, Dupuis, Reidy, & Nadon, 2007; Houger

Limacher, 2003; Houger Limacher & Wright, 2003, 2006; McLeod, 2003; McLeod &

Wright, 2001, 2008; Moules, 2000; Tapp, 1997, 2001; Thirsk, 2009; Wright & Bell,

2009; Wright et al., 1996), and the impact of family members witnessing the illness

testimony of other family members has also been reported prior to this (Duhamel et al.,

2007; Houger Limacher & Wright, 2003, 2006; McLeod & Wright, 2001; Tapp, 2001;

Thirsk, 2009). Yet how can we understand this aspect of the therapeutic process, what is

at play within these important moments of nurse-family interactions, how can our

understanding of this be broken open, or brought into question differently? This act of

witnessing and drawing forth illness testimony, in and of itself, appears to be interventive

in nature: these are what Gadamer (1989) might call events of understanding. This

witnessing of illness testimony invited changes into families' experiences of illness and

of suffering. The value of the nurse's presence and questioning is reflected in Jan's

words:

> *Jan (mother): I think your mom and dad will always be your mom and dad, and I think there are probably certain things that we wouldn't…see right to share, or… even know the value of sharing. Whereas when we were talking about having a neutral body…that would ask questions…that there was something that makes it easier when there is someone else, kind of, sitting, asking the questions.*

What is happening when illness suffering is witnessed, when the illness story is given testimony? And how did nurses and families work together to make these moments possible?

The Presence of the Nurse: Holding and Containing Suffering Within the Relational Boundary of the Therapeutic Conversation

I will start this exploration into the witness of illness testimony with the family's observation of the nurse's purposeful choice to adopt a 'neutral, third person' relational stance. I was fascinated by this family's use of the word 'neutral,' as the IBM (Wright & Bell, 2009) guides nurses to adopt a relational, nonhierarchical, and collaborative stance, which is based in part on the concept of neutrality, proposed in the 1980s by a systemic family therapy group known as the Milan team (Selvini et al., 1980). They proposed three specific guidelines for systemic work with families: neutrality, circularity, and hypothesizing. Drawing on the work of the Milan team, Wright and Bell (2009) described neutrality as the adoption of a specific attitude, or relational stance toward the family system in which the clinician does not take sides with any one family member, and there is a conscious effort not to blame the family, or any one family member in relation to the challenges they are experiencing (p. 118). Based on Cecchin's (1987) reading of neutrality, nurses also understand the importance of curiosity when adopting this relational posture: it was Cecchin's assertion that being curious "is the key element of therapeutic neutrality which invites the clinician to be constantly interested in alternative views and in inventing multiple punctuations of a behavior, interpretation, event, [or] relationship" (p. 407).

In turning to other disciplines, we find further literature on the adoption of this neutral posture within the therapeutic relationship. Miller (2002) articulated neutrality as

an "evenly hovering attention" (Miller, 2002, p. 84). Further, through an exploration of the shared knowledge of psychoanalytic theory and Zen Buddhism, Miller came to understand neutrality as the fostering of a particular stance towards the other which asks the clinician to allow "the other 'to be' in his own right" (p. 84). Hermeneutic philosophers also have something to add to our understanding of this relational stance. Caputo (2002) recently articulated the attention that Derrida and Lévinas have given to our "responsibility for, and to, the other" (Caputo, 2002, p. 513). These ideas possibly open up a new face of neutrality: it may be helpful to understand this relational stance as opening ourselves to what Derrida would call the 'in-coming of the other' (Caputo, 2002, p. 513):

> Language [and hence, dialogue/conversation] is for Derrida, as for Gadamer and Lévinas, always a matter of saying something *to* someone, addressing or being addressed by the other, hearing and responding to the other's word. The word of the other takes the form of what Derrida would call the coming or 'in-coming' (*l'invention)* of the other…For Gadamer, the incoming other is the fundamental 'risk' of hermeneutic understanding: to hear the other is to put oneself at risk. I doubtless bring my own interests to the table, but at the same time I do so in good faith…I expose myself to the other…in order to let the other be heard, and understood (Gadamer), to let the other come (Derrida), to let the other lay claim to me (Lévinas). In order to understand each other, we must ask each other to listen and we must try to be understood. Let us say that our exchange requires an air, a horizon, a field of amity or friendship. (Caputo, 2002, p. 513)

This spirit of listening to, understanding, as well as an opening to the 'in-coming of the other' is reflected in Ben's words:

> *Ben (father): Were those students...were any of them graduate students?...I think one of the reasons why...we enjoyed it so much is...there was an innocence about them...in their attitude. You know, "help us understand...help us see...help us...you know, help us go forward with you."...At the FNU, there was no blame assigned, it was complete understanding, complete acceptance*

In the opening to the 'in-coming of the other,' we also may find what Karen Horney (1987), a psychoanalyst, theorist, and feminist has articulated as a "meditative attitude of mindfulness and receptivity" (Westkott, 1997, p. 84) which is characterized by a "wholeheartedness of attention…being there altogether in the service of the patient [or family], yet with a kind of self-forgetfulness" (Horney, 1987, pp. 19-21). Horney asserted that this self-forgetfulness involves self-forget, but also being present with all your feelings, an attending to them as they emerge. This approach of meditative mindfulness and receptivity, might be similar to what Wright (1999) has understood as "moments of reverencing" (p. 63) within her Family Systems Nursing practice: "in those moments of reverencing there is a profound awe and respect for the individuals seated in front to you…I feel that same reverencing from family members being given back to me. In those moments of reverencing in clinical work something very special happens between the therapist and the family; it is something felt by all – a deep emotional connection" (p. 63). Wright asserted that it has been within those moments of reverencing that she has witnessed the "most profound changes in family members' thinking, behavior, illness experience, and most importantly, suffering" (p. 63). She further suggested that what is experienced in these moments is pure love, and she believes these moments are spiritual

in nature. Horney, I think would agree with Wright's (1999) observation of the change

than can be invited in by such moments, by adopting this relational stance:

> Horney believes that this 'attitude of wholehearted attentiveness' has a profound
>
> impact upon the inner life, inner structures, or core structure of the patient. She
>
> believed that the patient profoundly and deeply experiences…this neutral,
>
> meditative posture…The patient experiences this neutral, containing, caring
>
> presence, as an invitation to be and become. (Miller, 2002, pp. 85-86)

Here then, arises the notion of the containment or the holding of another, the

containment or holding of another's illness suffering within the relational space. This

research suggests that this relational stance, which is characterized in part by the

containment or holding of another, as well as the other's illness suffering, to be an

integral part of witnessing illness testimony.

To "Incline the Ear": "An Ethics of Hearing" (Caputo, 2002, p. 513).

Of great importance in the clinical work with these research families was the

nurses' openness and commitment to listen and hear their stories of illness. Within the

therapeutic conversations with the nurses, family members were given an experience of

being heard. This experience of being heard was deeply valued, and families stated they

had not experienced anything similar to this prior to coming to speak with the nurses at

the FNU. This interventive move is particularly significant given the experiences that

parents had had within the health care system of being unheard. One mother expressed it

in the following way:

> *Jan (mother): Here's what is very important…considering the team that you are*
> *working with……it's very important that those people that come together…like*
> *you had a very good team* [nurses at the FNU]*, and the fact that everybody was*
> *unbiased…open to hear what we were saying, and what we were thinking, what*

we felt…you could tell…by when they were responding to the conversations…that they were listening to us, and they were hearing us, that's very important..nobody at any point said, "oh, you're wrong to that that"…they hear what was being said.

In previous research on family nursing intervention based on the IBM (Wright & Bell, 2009; Wright et al., 1996), nurse researchers have similarly described the healing that families experienced from being listened to deeply, from being heard by the nursing team (Houger Limacher, 2003; Houger Limacher & Wright, 2003, 2006; McLeod, 2003; McLeod & Wright, 2001, 2008; Moules, 2000). In her qualitative research study on therapeutic letter writing, Moules (2000) wrote about the importance of acknowledging and hearing the "cries of the wounded" (p. 203). She asserted that "people need to know that their pain has been recognized, and their wounded stories of suffering heard" (p. 203). Within this research, the experience of being heard gave family members the permission to have their pain, to claim the pain and grief that they had been carrying. For the most part, this pain and grief had previously been left unacknowledged:

> *Karryn (mother): If somebody helps you to acknowledge your pain, and helps you to feel like, "you're allowed to have this…this is yours to have." And grieve it …grieve it now…do what you can to grieve. Like if they* [oncology families] *can get the right supports, and the right understanding, so that they can have that time …to really, really grieve it, and not fight it, and not pretend…"I'm gonna be the strong person and plow through this."*

Within the therapeutic conversations that she shared with nurses at the FNU, Karryn also described an experience of being embraced and encouraged while in the presence of her pain:

> *Karryn: That…embracing, encouraging… "you're gonna get through this, and you're allowed to cry, and you're allowed to be angry"…that allowing for whatever the parents are going through, and being there with them alongside them…that would have made it so much easier for me and Lauren.*

You will recall that what characterized the liminal state that I described earlier was the acceptance of pain and suffering: "the vulnerability, poverty and "naked-ness" of those in this condition opens them up to the limitations of the human condition, limitations which are usually masked or hidden by social structure" (Levine, 1997, p. 50); in this space of liminality, both family and nurse come face to face with a transparency or a breaking point which has exposed the flux beneath (Caputo, 1987, pp. 269-270).

Family members not only had the experience of being heard by the nurse clinician, and nursing team, but also as I discussed earlier, in being invited to witness one another's illness testimonies they had the experience of hearing one another differently, of hearing one another's suffering. Frank (1995), as well as Caputo (2002), conceptualized the hearing of the ill, the hearing of the other, as being an ethical practice. For Frank (1995), witnessing holds a call to receive illness testimony, and in that receiving, "testimony implicates others in what they witness" (p. 143). It may be that within this clinical practice, the invitation and support of family members in the witnessing of one another's suffering allowed family members to receive one another's suffering, and in that receiving what was opened up was a different experience of, a different understanding of their own suffering.

Within the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996), nurses work to uncover constraining illness beliefs, those that enhance suffering in an effort to offer new, facilitating illness beliefs, those that might lessen or alleviate illness suffering. What this research invites is a consideration of how family members, through giving testimony to illness suffering, may offer one another alternative, facilitating beliefs that may act to lessen the illness suffering of other family members. Ben (father)

experienced a severe clinical depression following his son's cancer treatment. Within the

therapeutic conversation, Ben attributed one of the triggers for his depression to a

comment that one of the oncologists made near the end of Cameron's cancer treatment.

The doctor talked with Ben and Jan about the possibility that Cameron may experience a

recurrence of his cancer or a secondary malignancy within the next five years. Within the

context of the therapeutic conversation at the FNU, Ben and Jan shared with each other

some very different illness beliefs about what the future might hold for their son, and

their family. In hearing the doctor's words, Ben had become overwhelmed by the

possibility of having to face cancer again, whereas Jan chose to search for a new normal,

and focus on the restored health her son was experiencing. The clinical excerpt found

below is from the family's third clinical session at the FNU:

> Ben: …you start hearing phrases getting thrown out as the treatment progresses…
> "well, expect cancer again in five years"…your doctor's said this to you, and my
> first reaction is, "why?" "Well, we've given him so much chemotherapy, that
> we've altered his DNA."

> Jan: And you know, they need to know when they say a sentence like that…

> Ben: …and so….today I have this fear that one day, five years down the
> road…we could be back….and…

Later on in the therapeutic conversation, the nurse inquires further about how these

parents have come to live with the ongoing uncertainties related to cancer:

> Ben: I struggle with a real fear…

> Jan: See, and that's where Ben is different…Stephen (older brother) and I were
> talking about that today…about this "what if," and a sentence that you gave
> us [nurses at the FNU]…because they [the children] were talking about
> "normal"…things aren't going to be like they were before…look for a new
> normal. And I think Stephen and I have both applied that…stop trying to make
> things…as they were before. And just move forward…and realize that now you
> have a new normal…we could live in fear, but it doesn't profit us, it doesn't help
> us. And so our attitude has been "so be it, when it comes, then we'll cope with it

…but right now, he's got health, and we've got health, and….

In our research interviews, Ben shared that in listening to his wife, and learning about her approach to living with this knowledge that one day their son may be diagnosed with a secondary cancer, he had come around to her way of thinking, choosing to focus on the life that they had to share together rather than the possibility of Cameron being diagnosed with cancer again at some point in the next five years.

For Arthur Frank (1995), the illness witness "speaks from having been there, but his testimony is less of seeing and more of *being"* (p. 140). Frank's thoughts invite a consideration of how the testimony of illness may not be about what someone has seen, but about inviting the ill, and those who love them, those wounded by illness, to enter into a different place of being. Caputo (2002) invoked the language of the scriptures to express what he called an "ethics of hearing" (p. 513). He has articulated this as a call to "incline our ear" (p. 513). In this "ethics of hearing":

> Every sentence comes to us with a friendly supplication, asking us, to 'incline our ear'…to bend down before what we hear or read so as to let it come, let it be heard. Indeed the language of the Scriptures is very helpful when it come to understanding this ethics of hearing, this ethics of friendship required for understanding one another…Every utterance takes the form of a supplication or, one might even say, a *prayer.* Every time I open my mouth, I pray you, hear me: every time you open your mouth, you pray me, listen. We pray each other's patience, hospitality, openness, receptiveness. I pray you, give me your ear. If I give you my word, as I pray I do, you must, I pray you, give me your ear. Do not harden or stop up your ears but open them up, do not hold your head up

'harden or stop up your ears but open them up, do not hold your head

high in vanity and self-love but incline your ear to the other. Understanding

then takes on a slightly miraculous quality, like opening the ears of a deaf man,

so that we require a certain Spirit to open closed and hardened ears, a hermeneutic

spirit of friendship. (Caputo, 2002, pp. 513-514)

Within the therapeutic illness conversation, nurses inclined their ears to the illness

testimonies of family members suffering in the midst of childhood cancer, but what may

be even more pivotal to the healing that family members experienced was the nurse's

creation of a therapeutic space and conversation in which family members were invited to

incline their ear to one another, bearing witness to one another's illness testimonies.

Understanding Illness Testimony as "Presentation"

When, as nurses, we commit to this "ethics of hearing," when we "incline our

ear" (Caputo, 2002, p. 513) to the suffering that is manifest in the illness testimony of the

other who stands beside us, then family members and nurses experience what Levine

(1997) has called a "presentation" (p. 44) of suffering. To further explore what I mean by

inviting a consideration of illness testimony as a "presentation" of suffering, I return to

the ritual process that Levine (1997) has created for his students in an expressive arts

therapy training program. Levine calls this ritual process a "presentation" (p. 44) because

students are asked to present an experience of pain and suffering from their own lives in

artistic form:

I call this process a "presentation" for several reasons. First of all, students are

presenting something; they are making something manifest to the group. In fact,

what they are presenting is themselves; they are showing the pain and suffering in

their lives. In presenting this way, secondly, the student must become present. The suffering that he or she is presenting must be made actual in the here and now; it must be re-enacted and re-lived. Moreover, the student is there with others who themselves must be present to meet with him or her. They must be acutely attuned to their own felt responses in order to join with the presenter in the way that he or she needs. Thirdly, the presence of the student is itself a present, that is, a gift; it is a gift offered to the group to which the group responds by offering feedback, gifts in exchange. When the presentation works, and it does not always work, both the presenter and the group become authentically present to each other and to themselves. The normal masks and defenses that we use to hide behind and protect ourselves are dropped. We face each other as suffering souls. This communion gives us the sense of community; what we have in common is our vulnerability and our willingness to confront it openly. (Levine, 1997, p. 44, 45)

Levine (1997) asserted that in order for the "presentation" to be effective, the story needs to be told through an artistic medium, because the "arts "make present"; they re-create in the living moment a suffering that has been" (p. 45). He suggested that "talking about" suffering allows the presenter to hold a distance from it, and as such, suffering is not then brought into being. When it is in artistic form, "it becomes real; we feel as if it were occurring for the first time. We can't help but be affected or moved by it" (p. 45).

What this hermeneutic interpretation of clinical work at the FNU suggests is that within the IBM (Wright & Bell, 2009) what is manifested is a particular way of being

with suffering; through the sharing of illness testimony, and an "ethics of hearing," suffering becomes present in the here and now, as if it were occurring for the first time. Similarly, when we consider the narrative ethics that Frank (1995) described, there is an understanding that "the only mode for receiving testimony….is *being with*" (p. 144). The illness testimony within the context of a therapeutic conversation is what Gadamer (1989) might call an encounter with aesthetic truth. We learn and understand ourselves in and through the aesthetic experience which is encountered in the sharing of illness testimony within the therapeutic conversation. We meet the art work, the illness testimony, in a world, and encounter a world in the illness testimony.

> Our experience of the aesthetic too is a mode of self-understanding. Self-understanding always occurs through understanding something other than the self, and includes the unity and integrity of the other. Since we meet the artwork in the world and encounter a world in the individual artwork, the work of art is not some alien universe into which we are magically transported for a time. Rather, we learn to understand ourselves in and through it…we must adopt a standpoint in relation to art and the beautiful that does not pretend to immediacy but corresponds to the historical nature of the human condition…The binding quality of the experience (Efrahrung) of art…is that art is knowledge and experiencing an artwork means sharing in that knowledge. (Gadamer, 1989, p. 97)

Similarly, experiencing an illness testimony which arises from the wound and suffering of the witness (Frank, 1995) means sharing in that suffering, and in that sharing, learning something about ourselves, as well as something about human life. Within

illness testimony, no longer are family members talking at a distance about their suffering, but rather, their suffering is called forward in such a way that it comes into being.

Illness testimony as gift. Levine suggested that in order for the "presentation" of suffering to work, it must have the "spirit of the gift. i.e. if it is truly a "present" and not a "performance"" (Levine, 1997, p. 51). Similarly, in order for illness suffering to be present in this way within the therapeutic conversation, it needs to be received as a gift. Family members do not consider their testimony a gift, but the nurse must receive it in that way. We might think of illness testimony as a gift of the inner world. Hyde (2007) noted that "the gifts of the inner world must be accepted as gifts in the outer world if they are to retain their vitality…where the gift as a form of property is neither recognized nor honored, our inner gifts will find themselves excluded" (Hyde, 2007, p. xix). Hyde (2007), in his discussion of creativity, the artist, and the history of gift exchange, suggested that "the way we treat a thing [a gift] can sometimes change its nature" (p. xvii). This research suggests that how the gift of illness testimony is received influences and affects its very nature. The nursing act of attempting to receive illness testimony as a gift, may be in part what allowed families to have an experience of their suffering being shared:

> Ben (father): And I think that's what the FNU did…they shared in our suffering
>
> Jan (mother): They…they could relate.

What discriminates this face of gift exchange from others is that the origin of the gift comes not from pleasure but a deep experience of pain (Levine, 1997). It is only when the suffering, when the wound is accepted and "borne" (p. 56) that it becomes a gift. When students are assisted within this process to bear or "own" (p. 57) their suffering,

then they, as well as those who witness that suffering become opened to experiences of increased vitality, wisdom, and even joy. For Levine (1997), art plays a central role in the bearing or owning of the suffering of each expressive therapist. In order for the student to be able to confront the wound, there must be a form in which it is contained. For Levine (1997) and his students, this container takes the form of art. For families participating in clinical intervention at the FNU, the container took the form of illness testimony within the physical, emotional, and spiritual boundary of the therapeutic conversation.

> Art [or here, the therapeutic conversation] provides the container in which pain can be "borne." Without this container, the psyche cannot "hold" its suffering: the intensity is too much to bear. Art creates the form in which intensity of feeling can be contained. This form does not eliminate or decrease the pain; rather, it permits intolerable sorrow to be accepted and "owned." Containment increases intensity. By making art out of suffering, the presenter acquires an "increase" over the mere undergoing of his or her fate; presentations often end with presenters experiencing a renewed sense of power and aliveness. (Levine, 1997, p. 57)

Similarly, this experience of renewed power, and aliveness was reported by families in relation to how they felt after participating in therapeutic conversations at the FNU:

> *Ben (father):* [After the family clinical session at the FNU] *Everybody…we'd get in the van and they're like… "whoa, let's go to Harvey's drive in and get a milk shake"…they felt good…they felt like they were… "I've been heard"…"I'm as much a part of this family, and I went through it…but this is how I went through it." I know for me, and I think for Jan, to hear…was a real eye opener… Cameron's, Stephen's perspective…I'll never forget Stephen, I mean…I think he flew out of here* [FNU], *like he was on cloud nine after the first session.*

The Return of and Labor Over the Gift: Opening Suffering to a Multiplicity of Interpretive Offerings

I have introduced an interpretation of Family Systems Nursing intervention based on the IBM (Wright & Bell, 2009; Wright et al., 1996) as approaching a form of gift exchange; a gift exchange that shares a remarkable kinship with the ritual process of gift exchange. It has been suggested that nurses within this specific context and practice model, received testimonies of illness as gifts, gifts that were borne out of the wounding of illness. What happened once the gifts of testimony were received by these nurses? What was done with these gifts of illness testimony, with the illness beliefs that were embedded within those illness testimonies? How were these gifts treated, how were they cared for? We could understand the caring for these gifts as a kind of "labor undertaken by the soul" (Hyde, 2007, p. 60), a labor that accompanied, or opened a possibility for transformation, for the opening of illness suffering to new possibilities. This might be understood as a labor which invited family members to a moment of reflection: "the moment when we become aware of that part of ourselves which we cannot see in any other way" (Maturana & Varela, 1998, p. 23). These gifts, what Hyde (2007) might call threshold gifts, showed themselves as a multiplicity of interpretive offerings brought forward in the context of a reflecting team.

One of the essential aspects of gift exchange is that the gift must always move. If the movement of the gift is lost, then the gift will lose its gift properties. Hyde (2007) suggested that this movement is like the continual flow of a river; the movement of the gift continues when one allows oneself to become a channel for the gift (Hyde, 2007). Interestingly, the preferred language for contextualizing nursing intervention within the IBM is the term "move" (Wright & Bell, 2009, p. 140); the word "move" is thought to

better account "for the seamless flow of conversation between the clinician and family in face-to-face encounters and long after – all of which is intended to be interventional in the softening of suffering" (p. 140). Might it be possible that the term "move" also accounts for the movement of the gift of suffering which flows through the very souls of the nurses who receive it? Hyde (2007) noted that the gift has an outer movement, it

> leaves all boundary and circles into mystery. The passage into mystery always
>
> refreshes. If, when we work, we can look once a day upon the face of mystery,
>
> then our labor satisfies. We are lightened when our gifts rise from pools we
>
> cannot fathom. (p. 25)

This may be what gives this clinical work such meaning for nurses who participate in it. For not only does one witness the abyss, the raging thunderstorm, a break down of what a family believed life to be, but you are also given a glimpse into the "face of mystery" (Hyde, 2007, p. 25).

Another way in which one can understand the movement of a gift is to "say that a gift must always be used up, consumed, eaten…food is one of the most common images for the gift because it is so obviously consumed" (Hyde, 2007, p. 10). This means:

> that the gift perishes *for the person who gives it away.* In gift exchange the
>
> transaction itself consumes the object. Now, it is true that something often comes
>
> back when a gift is given, but if this were made an explicit condition of the
>
> exchange, it wouldn't be a gift…a gift is consumed when it moves from one hand
>
> to another with no assurance of anything in return. (Hyde, 2007, p. 11)

This consumption, using up, or eating of the gift is what Levine (1997) is referring to when he speaks of "bearing gifts to the feast" (p. 43) in his portrayal of the

rite of passage experienced by expressive arts therapy students. The presenter's suffering is contained within an artistic form. Levine (1997) used the metaphor of a feast for understanding the consumption of this gift. He reminds us that the communion meal or feast "may be the earliest form of human solidarity…the feast is the original form of communitas" (p. 60).

> The "feast" then, is the event in which gifts are received and exchanged. The presentation is not complete until the "feedback" is given. Both presentation and feedback nourish the participants and give them renewed life. This "increase" of vitality itself demands to be given away…the gift must be given away if it is to stay alive. Only by being consumed or "eaten" does it generate an increase in vitality. (Levine, 1997, p. 60)

For Levine (1997), the consuming or feasting on the gift takes the form of "feedback" (p. 54), which is given to the presenter by the group who has received the presentation. Further, the feedback must come in a specific format, it is given back to the presenter partly in words, but in some way it must take an expressive, artistic form. Hyde (2007) asserted that there is circularity inherent in the movement that is characteristic of gift exchange. Further, as we engage in the ritual process of gift exchange:

> we come to feel ourselves as one part of a large self-regulating system. The return of the gift, the "nourishing *hau"* [also known as feeding the spirit, a ceremony performed by priests in the gift exchange rituals practiced by the Maori, the native tribes of New Zealand], is literally feedback, as they say in cybernetics. (Hyde, 2007, pp. 23-24)

What is intriguing here, is that cybernetics is one of the theoretical underpinnings of work within a Family Systems Nursing framework. Wright and Leahey (2005) draw on this theory to help nurses understand the clinical value of considering the family system as an interpersonal system that possesses self-regulating ability: "the behavior of each person affects and is affected by the behavior of each other person" (Watzlzwick, Beavin, & Jackson, 1967, p. 31). Within this hermeneutic interpretation, the nurse-family system is also understood as a self-regulating system in which the behaviors and gifts offered by the nurse have the potential to impact the family system, and each relationship within that system. Understanding the nurse-family system as a self-regulating system has been previously identified as second-order cybernetics (Slovik & Griffith, 1992). Within second-order cybernetics, there is an examination of the communication patterns not only between family members, by also an examination the "therapist's role *inside* the treatment system itself" (Mills & Sprenkle, 1995, p. 368).

The Reflecting Team: The Offering of a Multitude of Viewpoints, New Perspectives, and Interpretations of Suffering

One of the formats in which feedback is offered to the family from the nursing team within the IBM model (Wright & Bell, 2009; Wright et al., 1996) is through the sharing of thoughts, ideas, questions, and commendations within a reflecting team (Anderson, 1987, 1991). Just as the expressive arts therapy student receives feedback in a specific format, so there is a specific format for the feedback given by the nursing team. For families who participated in this research, the opportunity to listen and then respond to the conversation shared by nurses in the context of a reflecting team was particularly important to their healing.

After participating in the therapeutic conversation with a nurse clinician during the first part of the clinical session, family members were invited to sit behind a one way mirror to listen to the nursing team's conversations which focused on their reflections and observations of the dialogue between the nurse clinician and family. After this, the family and nurse clinician returned to the room, and the nursing team moved back behind the one way mirror to listen to the family's thoughts on the reflections that the nurses had offered (Anderson 1987, 1991; Wright & Bell, 2009). Within this "feedback" format, nurses are guided to offer their ideas, questions, and commendations in a particular manner. These include, but are not limited to, the offering of commendations, the acknowledgement of individual, relational, and family suffering, offering alternative views/beliefs about family member's relationships and experiences of illness, sharing personal and professional experience that relate to the family's stories, beliefs, and suffering, as well as offering views on questions that have been asked of the team by family members (Wright & Bell, 2009, p. 268).

What families found particularly helpful in receiving feedback through the offering of a reflecting team were the new perspectives or viewpoints given to them:

> *Karynn (mother): What happened* [at the FNU] *was…I would emote, I would talk would come up with ideas, I'd express myself…everybody would be listening… would be listening…and then there would be… "what about this?" "what about that?" All these wonderings…which were very fantastic in that they advance a kind of milieu where…we're basically taking my insides and putting them out… and then everybody's kind of looking at it and going, "well, what about this?" "what about that?" And so it's kind of like having a whole new set of viewpoints...I mean…if I could say what's the one strength of the FNU, it would be…that I've got fifteen…upwards of ten to fifteen different viewpoints… so, that's a real advantage of that kind of therapy…the reflective team.*
> You will recall that in my earlier discussion of the ancient lineage of the symbol

of the circle and the building of Rome, that the centre of the city was known as the

mundus, which was covered with a great stone, known as the soul stone. "On certain days the stone was removed, and then, it was said, the spirits of the dead rose from the shaft" (Jung et al., 1964, p. 272). One might understand the process of the reflecting team offered to families as a conversational lifting of the "soul stone," allowing a connection with ancestral spirits which allowed an evoking of a multitude of interpretations, at times opening up the possibility of glimpsing into the "face of mystery" (Hyde, 2007, p. 25).

Leaving Normal: Exploring One Nursing Reflecting Team Offering

> *Jason (brother): For me…the nursing unit was…the beginning of a new life… the beginning of normal…the beginning of our family again…it was awesome.*

During the fifth clinical session with the first research family, only the parents were present (Jan and Ben). As part of the process of concluding the clinical work, Lisa (nurse clinician) asked the following questions: *"What did you find most helpful in our work together here? What did you find least helpful?"* For these parents, one of the interventions that had been extremely helpful was an idea offered in the nursing reflecting team during the second clinical session. One of the nurses suggested that the family may never be able to return to normal; it may not be possible to return to the family life that they had known prior to Cameron being treated for cancer. Her comments from that reflecting team are included below:

> Joanne: There was a movie that was out, and I don't remember the movie…but the title came to me…I think it was when Breanna said, "we're still not back to normal." And the movie was called "Leaving Normal." And I was thinking…I don't know if families can go through this kind of experience and return to where they were…ever. And I think we put undue expectations on…families…that they return to normal. We return to a different normal…we leave what was. And in many ways…with growth, right? We continue moving on and create new normals in our life. And I wonder…if you keep believing you'll go back to the way things were…if then you'll continue to believe that you aren't moving ahead…

Jan (mother) and two of the older siblings in the family had talked about this idea at home following the clinical session. Within the research interviews, the family talked about how very helpful this idea had been to them. It had invited them to look for a new beginning, a new family, a new life together. Further, the change that had been invited into family life had been sustained for four years after the clinical intervention. It was in our first research interview that Lizzie spoke about how she and her siblings felt excluded from the family circle after Cameron was diagnosed with cancer. Having learned this, I asked her whether she felt any different after coming to the FNU with her family:

> *Lizzie: Like we were back in the circle, they actually knew our names again.*
>
> *Jason: Yeah, we were back in the, back in the tree.*

The nursing act of gathering the family together was very significant for these children, as well as other family members. It was not until they came to the FNU that they had sat together as a family to talk about their illness experiences. No one at the hospital had offered them this opportunity, and they had not been able to have these conversations at home. During my third research interview with Lizzie, Jason, and their parents, we spoke again about how coming to the FNU had allowed the siblings to feel like they were part of the family again, included in the family circle. Listening to the ideas of the nursing team in a reflecting team, and hearing commendations about each family member had had a profound impact on what these siblings, and their family believed about themselves and their experience with cancer.

> *Ben (father): I think too, as I recall, for all of you* [talking to Lizzie and Jason (siblings)], *you really enjoyed listening to the group of nurses…they rehashed what we had shared, and then you had the opportunity to eavesdrop behind the glass. I remember, often on those…you guys* [turning to Lizzie and Jason], *we would walk back to the car, would say, "oh, that was great…that was just awesome, that was so good to hear those things!"*

Jason: Yeah, it was all fun.

Interviewer: So, what made it fun for you?

Lizzie (sister): To go back behind, and watch through the window…and then…

Jason (brother): And also…you make up fun things…we'd tell good things about each other, we'd all have a laugh…and you'd just explain the issues…we'd just like get through them, and then we'd…do something fun…

Interviewer: So, the talking about good things about each other…when do you remember doing that?

Jason: I remember…we went behind the glass…and you guys came in [nursing team at the FNU]*, and you'd tell what you like about us…like this one is athletic, and this one's in charge, that one was smart …we all liked that. And then we came in, we all talked about, we had a good laugh, we all had fun.*

Interviewer: And did that help change…how you thought about your family, or how you thought about Cam being sick?

Jason: Oh, yeah! [marked emphasis] *Like…when Cameron was sick, I was like, "oh, my parents don't love me…they want to spend all the time with Cameron, I got no family." And then we went to the FNU, and we had fun, and I realized that my family was like any other…we just went through…a hard…trauma…a traumatic situation, experience…so otherwise, we're a normal family.*

Interviewer: So, it sounds like you came to believe something really different about your family.

 Jason: Oh, yeah!

Interviewer: And how did that change…your life at home together with your family? Did it change anything?

Jason: Yeah…

Lizzie: …our whole life's changed…everything…[family laughs together]

The Transformation of One Parental Illness Belief: I Need to Teach my Children That Difficulties Will Come In Life – It is Through Facing Difficulty That We Can Develop Character, Endurance, and Even Compassion

Earlier in this research, thesis I discussed the intense suffering that parents experienced in their inability to protect their children from harm in the context of a child being diagnosed with cancer. For parents, there exists an innate and unrelenting drive to protect their children from harm. Within the experience of a child being diagnosed with cancer, it becomes impossible for parents to protect the ill child or his/her well siblings. During the course of clinical intervention at the FNU, one mother experienced a transformation in what she believed her parental role was in relation to protecting her children from harm. As I reviewed the videotapes of the clinical work with her family, I came upon this surprising, and quite dramatic change in Jan's belief about her role as a parent. What was intriguing was that this change had not been recognized by the nurse clinician or nursing team. The illness belief that was constraining, and inviting suffering into Jan's life was distinguished within the clinical work as Lisa, the nurse clinician, attempted to externalize some of the internalized questions which family member's were asking themselves in the context of their illness suffering (Wright & Bell, 2009). In response to this nursing inquiry, Jan (mother) shared her belief that as a parent she was supposed to protect her children from the struggles and hardships of life. Below is a short excerpt from the first clinical session at the FNU:

> Nurse Clinician: Lots of times when families and individuals are faced with times of difficulty, they find…you ask yourself questions… "Is this going to get better? Are we going to get through this?" So, if there's one question going through your head, that you would like to have an answer to, what would that be?

> Jan: Sometimes as a parent, I've even asked myself the question…you strive very hard for them, but sometimes you wonder what the purpose of striving so hard for them is. I think if their parents are guilty of anything, it's striving to keep them,

and spare them…from some of the hardships and struggles of life. Well there's a hardship and a struggle [pointing to Cam/child with cancer]…that forget it, you can't even begin to…

Ben (father): You can't protect them…what Jan's alluding to …loss of control, absolute…loss of control.

It was within this research analysis of the clinical work that this belief was identified as a potential core constraining illness belief for this mother. Further, within the clinical excerpt you can see that Ben also struggled with his inability to protect his children from the hardships of life. In the fifth clinical session, which occurred six months after the first session, there was a marked change in Jan's illness belief. During that session only the parents were present. The nurse clinician had repeatedly asked the parents if they had concerns or questions that they would like to attend to within the session, but they were unable to specifically identify a focus for this session. Given this, the nurse clinician asked the parents if they would consider answering some questions that the nursing team had found themselves wondering about. The parents expressed their openness to this, so the nurse clinician asked a series of questions which focused on the parent's beliefs about meaning, purpose, and spirituality. Within this inquiry, Jan shared with Lisa a new, facilitating belief about her role as a parent. She had come to believe that as a parent, she needed to teach her children that difficulties will come in life, and that it is through facing difficulty that we can develop character, endurance, and even compassion. Below is an excerpt from the fifth clinical session:

Nurse Clinician: One of the questions we were wondering about was…in thinking about making meaning of…purpose of things…those spiritual questions: What is the meaning? What is the purpose? How do you answer the question, why us?

Jan: If life was always rosy and good, and we don't have the challenge and difficulties, which are part of life…we won't develop the strength of character, and endurance, even compassion. And one thing that we've learned as a result of

cancer in our family was…life is a difficult journey. Sometimes you choose your own difficulties, and other times, the difficulties come because of circumstances not of your choosing. But they're going to come, so when they do, what are you going to do? I think as part of…parenting…we have to be realistic with our children, and tell…life is going to be difficult, it isn't going to be a bed of roses.

What contributed to this profound shift in Jan's belief about her role as a mother?

In reviewing the videotaped clinical sessions a second time, I found a segment at the end

of the reflecting team in the first clinical session where the nursing team had explored

this illness belief, and offered an alternative, possibly more facilitating belief. That

transcribed segment of the reflecting team is included here:

> Christine: I…find myself thinking about these parents…how do you save your children from these hardships? I think as a parent, you're always wanting to protect your children…for them to have, to give them the best life, the happiest, the most joyful life that they can have. And just the suffering that must come with that…knowing that they couldn't protect Cam from cancer, and they couldn't protect Kathy from the challenges that she's had in the past. And how as a parent, that must be so very difficult, to desperately want so much to protect your child… and to have to witness them suffering that way…And I think coming here…did take such courage on their part, to talk about that.

> Joanne: It was the love, and the respect…there was something palpable about…the maturity…lets speak to just the youngest member of this family, Jason. That he could come and sit for two hours respectfully contributing, showing his own sensitivity, and talking about the stress that he wants gone. And Lizzie, comforting her sister, at times I thought, and being comforted by her…Every single member of this family…we could walk through each one. I just thought what a testament to these parents...

> Lisa: I was looking at these questions that they had all asked….very different questions, but a very similar theme: Is there an end? How do you cope with the loss of control? …put the pieces back together? When will I be able to sleep?

> Joanne: And even around…is it going to be bumpy? Is this what we're going to expect, that there's going to be bumps in the road? I wonder if this is a family who hasn't has a whole lot of hardships in terms of…bad things coming their way. And I wonder if this sort of was a shocking…because it is a worse nightmare kind of shock…All of a sudden you think, that life is pretty predictable, things have been going fairly well, and we think that you can keep your kids safe…to learn that there are bumps, that life is a bumpy road. And I wonder if…there might be …some wisdom that is embedded in all the horribleness of this experience. To

expect, that sometimes there are bumps, and sometimes going over them, makes the ride…not always smooth, but it…makes you a better driver, to know you can navigate them.

Within the dialogue shared by members of the nursing team, what stood out for me was the constant presence of questions. There are new ideas, new interpretations offered, but they are offered in a very particular manner; they are offered to the family in the form of a question. How might we understand the prominence of questioning within these nursing reflections? My first inclination is to turn to the Maturana and Varela's (1998) Biological Theory of Cognition, which is one of the theoretical underpinnings that guide clinical intervention based on this practice model. Previously, Houger Limacher and Wright (2006) noted the history between this biological theory and the specific use of the word "offering" (p. 322) within the IBM (Wright & Bell, 2009; Wright et al., 1996). Maturana and Varela (1998) proposed that as human beings we are structurally determined, and as such, our nervous systems are operationally and informationally closed: "it is the system in constant interaction with its medium that specifies how it will behave, not the information or instruction" (Wright & Levac, 1992, p. 915). Based on these ideas, nurses come with an assumption that ideas can only be offered, that it will be the fit between the interpretive offering and the family's structure that will determine whether a specific idea is helpful to a family. This unique approach to the offering of clinical intervention did not go unnoticed by the families:

> *Interviewer: Some of those ideas that were really helpful for you…was there something in the way those were offered to you?*
>
> *Ben: Absolutely! They were offered…out there for you to consider…so, it left me and I think the kids…that's why they liked it so much…you put it on the table, and it's there for me to choose…to accept, you know?*

It is also possible to understand the impact of this questioning stance from a philosophical viewpoint. Gadamer (1989) suggested that the openness which characterizes hermeneutical consciousness is linked inextricably to the question, and the questionability of experience itself. It is the arising of the question that makes possible the breaking open of the very being, the ontological nature of the topic that lies before us. Thus, the asking of questions opens the possibility of breaking open the suffering that is brought into being within the therapeutic conversation.

> The structure of the question is implicit in all experience. We cannot have experiences without asking questions…the openness essential to experience is precisely the openness of being either this or that. It has the structure of a question ....A question places what is questioned in a particular perspective. When a question arises, it breaks open the being of the object, as it were…people who think they know better cannot even ask the right questions…Discourse that is intended to reveal something requires that thing be broken open by the questions.
>
> (Gadamer, 1989, pp. 362-363)

Further, the ability to ask good questions, questions which have the potential of breaking open the being of suffering, is not easily done. To ask good questions, to pose a question requires that we are experienced in the life world of the topic. They arise, press upon us, from the nursing practice we stand in the midst of.

When I had the opportunity to ask Jan how she understood this transformation in her beliefs about parenting in the context of such a serious illness, she connected this change to the new perspectives she had received at the FNU:

> *Jan: I think very much when children are little, we have that control in our hands… we definitely* [emphasis] *on a cancer journey, lose control of…and as*

tough as it is... it makes you richer...you're experiencing an aspect of life that you would never put yourself in... But I think it's very important to...in order to come out the other side...of a very tough situation, to have much more this nursing unit ...a 100%, like it...you should be part of that journey, from the beginning. Those parents [of other oncology patients]*...a lot of them do come out broken...because they haven't been able to see another perspective...they're so consumed... absorbed in their thinking...they need to be able to think other things...*

Interviewer: So there seems to be something really important for you about seeing that new perspective...

Jan: Definitely! [emphasis]

Ben: There's a change in perspective...

Jan: See something positive...for a change.

How can we then understand the way these new perspectives invited such change to this parent's belief between the first and fifth clinical session, despite no extensive exploration of the belief in other clinical sessions? If we revisit the consideration of the reflecting team feedback as a threshold gift returned to the family in gratitude for the gift of suffering received through illness testimony, we will recall that such gifts do hold the possibility of transformation. Here we remember that as nurses we are attempting to approach an experience, or a place of gift exchange, but certainly not all ideas, thoughts, questions, or perspectives offered by the nursing team will be received in a manner that allows them to invite change. Hyde (2007) suggested that when gifts are received:

It is as if such a gift passes through the body and leaves us altered. The gift is not merely the witness or guardian to new life, but the creator. I want to speak of "teachings" as my primary example here. I do not mean school book lessons here, I mean those infrequent lessons in living that alter, or even save, our lives...the "teachings" are in passage in the body of their recipient between the time they are received and the time when they have sunk in so deeply that they may be passed

along. (pp. 57-58)

It may be that some of the "teachings" offered within this clinical intervention took time to pass through the body of their recipient; if we return to Maturana and Varela's (1998) biological theory of cognition, it may be that some perturbations, although a 'fit' with family members individual biological structures, may require some time to bring about changes within those structures. This invites a new understanding about therapeutic change: at times, there may be a mystery to this process, and the fruits of a gift may not become visible to nurse and family during the process of intervention.

Concluding Thoughts

> *Lizzie (14 year old sister): Well see, when you're in the hospital with your children for six months, a year, or for the rest of their life, you get disconnected from all your other children. So if you have an opportunity to sit down with the whole family…with your children, and talk to someone about what's going on, and just open up and share...you should take it cause it would really show…what everyone is going through. Because even though you're at the hospital, your children at school, or the house…you don't know what's happening. Like, at times, I cried myself to sleep at night and I could hear Jason in the other room and…there's just so much that goes on, that no one really knows. Like even my sister Rachael, even though she was always home, or we were gone, and we would come home…her eyes would just be bright red from crying, and you could see the tear going down her…so take a chance, or the opportunity to sit down with the whole family and talk. It would really help.*

Family intervention with each of the families in this research was complex and multifaceted. Illness suffering existed not only at the family level, but also showed itself in different forms at various relational levels. The intensity of this illness suffering and the profound changes in the lives of all members of the family are echoed in Lizzie's words. The interventional practices which are most helpful to families living with childhood cancer have been explored within this thesis chapter.

Nurses, guided by the IBM (Wright & Bell, 2009; Wright et al., 1996), created a context for change by gathering the family and nurse together, and creating a physical, emotional, and spiritual boundary in which illness suffering was called forward into being, shared between nurse and family, as well as between family members. It is this relational boundary that facilitates family members' bearing witness and giving testimony to one another's unique experiences of illness suffering, a process which allows them to own or claim their pain, as well as to learn about and begin to understand one another's suffering. It is in the sharing of suffering that healing is found, a sharing between family and nurse, but also between different family members. Essential to the process of lessening illness suffering is the presence of the nurse as a neutral, third party person, acting to hold the family in the midst of conversation, receiving and containing the suffering, and allowing different family members to adopt a reflective, listening, witnessing stance. In the sharing of their illness suffering, at times family members themselves offered one another new interpretations or beliefs about illness suffering, beliefs that invited a lessening of illness suffering in family life. Also integral to this process is an "ethics of hearing" (Caputo, 2002, p. 513). When nurses receive illness testimony as a gift, family members have an experience of their suffering being heard. The therapeutic conversation, and specifically the illness testimony provides a form in which to contain suffering. It is this containment, or holding of suffering, that allows the opening of suffering to new perspectives, interpretations, and illness beliefs. Also essential to this process of healing is a relational attentiveness to family strength which was drawn forth through the offering of commendations (Wright & Bell, 2009; Wright & Leahey, 2009; Wright et al., 1996).

Within the final chapter of this thesis, I will explore the implications of inviting the presence of a gift relationship marked by creativity, generosity, reciprocity, and human kindness into our nursing practices in the effort to address more fully the illness suffering experienced by family members in the context of childhood cancer. Within that discussion, I will consider how intervention at the family level within childhood cancer care might be understood as a health promotion practice. Implications for nursing practice, education, and research will also be considered.

CHAPTER TEN: THE APPLICATION OF KNOWLEDGE: HOW MIGHT THIS RESEARCH INFORM FAMILY INTERVENTION IN THE CONTEXT OF CHILDHOOD CANCER?

Attending to the Narrowing and Opening of the Heart: A Need to Enhance the Holistic Care of Child and Family

Red Bird

Red bird came all winter
firing up the landscape
as nothing else could.

Of course I love the sparrows,
those dun-colored darlings,
so hungry and so many.

I am a God-fearing feeder of birds.
I know He has many children,
not all of them bold in spirit.

Still, for whatever reason-
perhaps because the winter is so long
and the sky so black-blue,

or perhaps because the heart narrows
as often as it opens-
I am grateful

that the red bird comes all winter
firing up the landscape
as nothing else can do.

Red Bird Explains Himself

"Yes, I was the brilliance floating over the snow
and I was the song in the summer leaves, but this was
only the first trick
I had hold of among my other mythologies,
for I also knew obedience: bringing sticks to the nest
food to the young, kisses to my bride.

But don't stop there, stay with me: listen.
If I was the song that entered your heart

> then I was the music of your heart, that you wanted and needed,
> followers: gardeners, lovers, people who weep
> for the death of rivers.
>
> And this was my true task, to be the
> music of the body. Do you understand? For truly the body needs
> a song, a spirit, a soul. And no less, to make this work,
> the soul has need of a body,
> and I am both of the earth and I am of the inexplicable
> beauty of heaven
> where I fly so easily, so welcome, yes,
> and this is why I have been sent, to teach this to your heart."
>
> (Oliver, 2008, pp. 1, 78[4])

The experience of having a child diagnosed with cancer profoundly affects all members of the family. The emotional, social, and spiritual lives of family members are deeply impacted by the presence of cancer in family life. Within their experiences of illness suffering, family members face a narrowing of the heart, a narrowing of their very spirits. The care of family members' experiences of emotional and spiritual suffering was something that for the most part had not taken place within the health care system as a part of their journey through childhood cancer. Yet, this is an aspect of health care provision that families identify as being vital to their healing, and to their ability to carry on in family life beyond the experience of cancer.

Families experience the care of the body, the treatment of the disease of cancer, to be exemplary within the health care system, but for the most part, they did not experience holistic, comprehensive care for the entire family. What this research suggests is that within present day health care provision, the need of the body for a song, a spirit, a soul (Oliver, 2008), somehow is not appreciated deeply enough within the nursing care and

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[4]From *Red bird: Poems by Mary Oliver* (pp. 1, 78), by M. Oliver, 2008, Boston, MA: Beacon Press. Reprinted with permission.

nursing intervention practices that are presently being offered to family members. When

this care is not provided, what families can be left with is a continued narrowing of the

heart and spirit, a narrowing of family life, despite the curing of disease. Families spoke

about the need to better attend to holistic care for the entire family unit repeatedly over

the course of family systems nursing intervention at the FNU, as well as throughout the

research interviews that I conducted:

> *Interviewer: I'm wondering…because you talked a lot about how in the hospital the medical care was…the physical care was superb…*
>
> *Jan (mother): Uh-huh* [with emphasis]
>
> *Ben (father): It was for Cameron* [ill child], *and none for us.*
>
> *Jan: But I think it goes right back to the very, very beginning to where…a lot of the issues are…emotional issues, or psychological issues…issues that the cancer team is not dealing with. The cancer team is dealing with the physical* [emphasis], *and conquering, and curing* [emphasis]*…the physical…and there isn't somebody there that's realizing that…like I say, there's more to a human being than just their physical body* [emphasis on 'physical body']*…we're made of more than just the physical…if I ever have the opportunity to share with someone…beginning cancer…what do you recommend? You need some kind of an outlet…to cope with these things…*

What was particularly troubling for me as a researcher and a nurse were some of

the interactions that families had experienced with some of the nurses involved in their

care:

> *Jan (mother): Yeah, and again…the nurses on the ward would never…*
>
> *Ben(father): Never…*
>
> *Jan: No…they would never…they're attacking the physical…all the way… making sure you're physically comfortable…they're physically doing…the job that they've been assigned to do…there was very little time to sit…*

Families understood that for the social workers, nurses, and physicians involved

in their cancer care, there were many restraints placed upon them by the larger

administrative system that they worked in and that framed the nature of the care that

families received. Further, there were moments with individual professionals in which

family members did experience the giving of time, presence, and an attending to their

spirits beyond the care of the physical:

> *Ben (father):* [Ben is speaking about his interaction with an oncologist]...*He said, "I'm gonna be here...we'll just sit here together, and as things pop up in your mind, feel free to ask." And that...turned out...to be a very beautiful experience, because...he's not rushed to see other patients...he was there, and I remember, because by then I'd already spent two sleepless nights...to this day, when I see Dr. O'Donnell... there's a bond there, you know?*

Holistic nursing care, the attention to and healing of emotional and psychological

issues was what families felt was addressed in the Family Systems Nursing intervention

they participated in at the FNU.

> *Jan (mother): I think the thing that the nursing unit did was what the hospital was unable to do. And that was...you helped in the healing of the emotional, the psychological...the social, the family unit...The hospital had no ability...*

> *Ben (father): No time* [emphasis]…

> *Jan: No time...and no...knowledge, I don't think...they have one focus...and that is...conquer* [emphasis]…...*the cancer...*

> *Ben: And conquered it is...*

This family remains very thankful for the curing of their son's cancer, but for

them, as well as other families, there was something very important that was not

addressed within the care provided by the health care team. For the most part, attending

to the emotional and spiritual wounding of child and family did not happen in the way

that it needed to. Moore and Komras (1993) drew attention to the distinction between

care which is holistic (what they call patient-centred) to that which is not:

> The essence of patient-centred [holistic] care is reflected in the subtle difference

between curing and healing. Largely, the…health care system is focused on

curing…healing, however, makes one whole or well. It implies an integration

of body, mind, and spirit. Whereas curing focuses on the disease or injury, healing

focuses on the person experiencing the disease or injury…When health is the goal,

the definition of success is expanded to include what the patient has learned and

how well the patient is able to [live] even though complete curing may not be

possible. Healing implies that patient care operates on several levels: mental,

emotional, and spiritual, as well as physical. It implies that patients [and families]

are provided with the…resources they need in order to use their experiences of

illness as an opportunity to learn about themselves and to move toward a sense of

well-being. (p. 53)

Accounting for the Extension of Knowledge: Illness Suffering, Illness Grief, and New Possibilities for Intervention at the Family Level

The IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996), which

guided the interventional practices studied in this research, offers one advanced nursing

practice model that can help nurses and other health care professionals to address the

illness suffering of children and families who are living with childhood cancer. During

their clinical work at the FNU, the specific nursing interventional practices that facilitated

a lessening of illness suffering for families living with childhood cancer included the

particular relational stance adopted, the gathering of the family together for a therapeutic

conversation, assisting family members to bear witness to one another's experiences of

illness suffering by helping them to enter a reflective listening stance in one another's

presence. It was helpful to family members to have the nurse present as a neutral, third

party person who acted to hold and contain the illness suffering by receiving the illness

testimony/story. Questions and nursing responses that invited family members to externalize the internalized questions they were asking themselves, or the internalized conversations that they were having with themselves about their illness experiences were particularly helpful in lessening illness suffering. In externalizing these questions, family members were often assisted to hear one another's experiences of illness for the first time or in a different manner than had been possible prior to the intervention.

Some of the internalized questions that were asked by family members included the following: "why me?" "why our family?" "when will we be back to normal?" "when will this end?" "who am I now?" (parents) "what must people think about what kind of parent I am?" "do my parents love me?" (well siblings). One of the illness beliefs that was constraining for family members was the belief that life had changed irrevocably. Families experienced a profound loss of normalcy in day to day life, and were waiting for and expected to return to the normal they had once known. The suffering invited into family life because of these beliefs was related in part to the many changes in family relationships, roles, and routines, but there was also an intense spiritual longing to return home, to feel once again safe, secure, and grounded in family life and in the world.

Within this hermeneutic interpretation, there has also been an exploration of the many different experiences of loss and grief that family members experience within illness. These included the previously discussed loss of family normalcy, in addition to physical, relational and symbolic losses, anticipatory grief, illness survivor grief, and losses related to the death of fellow cancer patients. Grief has been explored as an integral part of the family experience of illness suffering in childhood cancer. This research points to a need to more clearly understand the various losses experienced by

family members within childhood cancer, and a need to distinguish losses that have already occurred from those which have a more anticipatory character. The Dual Process Model of Coping with Bereavement (1999, 2001, 2010) was proposed as one contemporary conceptualization of coping with loss that may be applicable to clinical intervention with families living with childhood cancer. Supporting and exploring the movement between the orientations of loss and restoration was evident in the clinical exemplars presented. The need to re-enfranchise the losses that are a part of illness suffering was highlighted within this research.

Parents within this doctoral research suffered in relation to an instinctual, unrelenting drive to protect their children from harm. Previously, researchers have described the split and separation in the family unit that can occur with childhood cancer (Björk et al., 2009; Clarke-Steffen, 1990, 1993, 1997; Fletcher, 2010; Kelly & Ganong, 2011; McCubbin et al., 2002; McGrath et al., 2005; Moody et al., 2006; Nicholas et al., 2009; Patterson et al., 2004; Woodgate 2001, 2006a). What is new within this research, is an understanding of how the drive to protect ill and well children from further pain and suffering, may play a part in the creation of distinct family groups (ie. mother and ill child at the hospital, father and well siblings at home). Further, parents often are not fully aware that this separation of the family unit has occurred as they adapt to a new life in the presence of cancer.

For siblings, there was an experience of being excluded from family life, in which they experienced the very loss of their parents during the treatment period. At the time of diagnosis, due largely to prolonged separation from their parents, siblings believed that they were no longer in the family circle, and that their parents did not like or maybe even

love them any more. They believed they were on their own to face a profoundly altered and difficult family life. Limited information and conversation about the illness enhanced their experience of separation and isolation within the childhood cancer experience. What is new within this research study is how Family Systems Nursing intervention based on the IBM (Bell & Wright, 2011; Wright & Bell, 2000; Wright et al., 1996) can work to invite siblings back into the family circle, and give them the opportunity to share their own unique experiences of illness suffering with other family members within the context of a therapeutic conversation.

Within the process of clinical intervention, family members experienced increased compassion for each other, and for the uniqueness of one another's illness suffering through the externalization of family members' internalized questions and conversations. Once nurses had facilitated the sharing of illness testimonies in the presence of other family members, there was an opening created for new illness beliefs or interpretations of illness. This occurred as they became aware of what other family members had been thinking and feeling during the time of illness. For example, upon hearing their parents' experiences of caring for Cam (ill child) in the hospital, Lizzie (sister) and Jason (brother) understood why their parents had not been home, why they had been largely absent from the siblings' day to day lives during the period of treatment. The anger and jealousy that they had felt was lessened, and replaced with understanding and compassion for what their parents had been through.

Also pivotal to the challenging of constraining family illness beliefs was the offering of alternative, facilitating illness beliefs in the context of a nursing reflecting team. The nurse's ability to explicitly attend to the illness and anticipatory grief within

the therapeutic conversation was another important aspect of the intervention process. And finally, the intentional acknowledgement and speaking about family strengths through the offering of commendations (Houger Limacher, 2003, 2008; Houger Limacher & Wright, 2003, 2006 Wright & Bell, 2009; Wright & Leahey, 2009; Wright et al., 1996) within the therapeutic conversation was essential to inviting family members into new perspectives and beliefs about their family and their illness suffering.

What implications do these findings hold for the provision of family care within childhood cancer? Is there an obligation to address the suffering of family members in a more comprehensive manner? Whose role is it to provide that care? These are some of the questions opened up by this inquiry.

Understanding Family Systems Nursing Intervention in Childhood Cancer as Health Promotion

Within this hermeneutic interpretation, I have suggested that family intervention which is guided by the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996) approaches the realm of gift, that it holds a kinship with gift exchange. Yet there lies here a difficulty, for as nurses working in administratively driven health care systems, we do not always practice in the realm of gift, what Hyde (2007) has conceptualized as a creative or artistic process and place of being. Rather, we find ourselves embedded in a world of economy, of commerce and knowledge exchange. The realm of financial resources and professional knowledge exchange is a place in which the commitment to approaching the realm of gift and creativity is not natural or easily accomplished.

Caputo (1997) noted that even within the realm of gift, one comes up against a paradox, as the sharing or movement of a gift inherently involves an element of exchange. Furthermore, it is the circular exchange of the gift that leads to its greatest limitation: "the

very thing that makes the gift possible also makes it impossible…because an exchange is a more or less economic transaction in which things of equivalent value circulate between parties" (p. 142). As agent, as professional, one can never break out of this circle of exchange that is created by the gift: "for as soon as a "subject" "intends" to "give" a "gift" to someone, the whole thing comes undone, the cycle of reappropriation is set off, and the gifts starts to annul itself" (p. 144). Caputo suggested that Derrida's way out of this bind, this entanglement in the exchange or circle of the gift, is to push against this very limit:

> …to make a passage to the limits, to embrace impossibility, to try to do the *im*-possible….The gift "calls" upon us for an expenditure without reserve, for a giving that wants no pay back, for distribution with no expectation of retribution, reciprocity, or reappropriation. To give a gift requires that one then forget…the gift calls upon us to tear up the circle of time, to breach the circular movement of exchange and reciprocity, and in a "moment" of madness, to do something for once without or beyond reason, in a time without time, to give without return. (Caputo, 1997, p. 144)

Yet, we are left with the very impossibility of this gift without reserve. In Caputo's (1997) reading of Derrida, what is articulated is Derrida's tracing of "the "gap" that lies between

> …the "gift if there is one" – that which is never present, which never makes an appearance, which is nothing, present, extant, existing, which what we most deeply desire – and "economy" – the domain of knowledge, philosophy, science, and exchange; of entities determined and exchanged, of calculation and balanced

equations, of equity and sound reason, of laws and regularities…it is never a

question of simply choosing between these two, between "economy" and the

"gift"…"we" "agent/subjects" are always to be found somewhere "between"

two, *in medias res,* in the gap of space between the gift, if there is one, and the

economy…It is never a matter of deciding for one rather than the other…would

never be a question of finding some place that is simply outside of the circle, but

of *interrupting* the circle, transgressing and breaching it, throwing away the

security of the circle, if only for the "moment." (Caputo, 1997, pp. 145-146)

For the families living with childhood cancer, abandonment of the search for this

space between gift and economy can lead to nursing care in which the body of the ill

child, the physiological care of the disease, becomes the primary focus. Involvement of

family then relates primarily to the care of the body, rather than intervention focused on

the unique human suffering experienced by family members, the suffering that occurs

within family relationships and at the level of the family unit. This is what Frank (2004)

might speak of as the loss of generosity in the family-professional relationship, a place in

which the face of the other, the suffering of the other, is not encountered or engaged.

Here, we do not put ourselves at risk as professionals, or carry any obligation for opening

ourselves to what the suffering of the other has to teach us about human life and the

experience of illness.

It is this space between gift and economy where an "ethics of hearing" (Caputo,

2002, p. 513), the bearing witness to suffering, and the re-interpretation of suffering

through the offering of new perspectives on illness, becomes possible. This is the space in

which the pain and grief of suffering can be claimed, owned, and may even be

transformed. Caputo (1997) invokes the reader to give economy a chance, and that we must do, but he also calls for the gift, the approach of the gift to make its way into our economies, into the economic and knowledge exchanges that frame the nursing care of families. The danger lies in the creation of an economy or exchange in care provision that becomes defined as solely "contractual relationships "with no "give," no gifts" (Caputo, 1997, p. 150). Here, families may be left with profound experiences of unattended illness suffering.

Keeping in mind these times of fiscal restraint, limited financial resources, and health care reform, do we nevertheless have an obligation to provide this level of family intervention? Whom should we see as the focus of care provision, the ill child or the family unit? One might argue that inviting the gift into our economies is not efficient, it would cost too much money, that this is family therapy not nursing, and families do not enter the health care system to receive therapy, but rather for the curing of their child's disease.

To answer these critiques, I will turn to the calls that have recently been made for reform in health care, reform that invites a greater focus on health promotion within the delivery of Canadian health care (Epp, 1986; Hamilton & Bhatti, 1996; Hancock & Perkins, 1985; Health Canada, 1996; Lalonde, 1974; WHO, 1986). What I propose is that attending to illness suffering in the context of childhood cancer through nursing intervention at the family level should be understood as a practice in health promotion. Further, this practice should not only be pursued because it is what should be done, but also because it represents "upstream thinking" within a socioenvironmental approach to health (Wilkinson, 1996, p. 64), an approach that has been articulated and promoted at

both a national and international level, in part, through a pivotal health policy document, the *Ottawa Charter for Health Promotion* (WHO, 1986). It is important that health promotion and disease treatment be considered not as completely separate activities in health care, but that we begin to explore how health promotion practices can be embedded within or delivered in partnership with the acute care treatment of chronic and life-threatening disease. Within *Achieving Health for All: A Framework for Health Promotion* (Epp, 1986), another foundational health policy document in Canada, the enhancement of coping mechanisms within context of chronic illness was acknowledged as one of three major challenges that require increased attention within health care.

The nursing practice of inviting families to engage in family level intervention in childhood cancer may save the health care system significant amounts of money by preventing the need for mental health intervention in the years following childhood cancer treatment. Within this research study, multiple family members required intervention for clinical depression and post-traumatic stress symptoms during and following the ill child's cancer treatment. Mental health intervention was needed not only for some of the children who had been treated for cancer, but also their parents and previously healthy siblings. As discussed earlier in chapter six of this dissertation, one of the ill children did not receive psychiatric care for post-traumatic stress syndrome until he came to the point of considering suicide, months after the completion of his cancer treatment. Within the research literature, there has been growing attention within the field of childhood cancer to the need for family level intervention, particularly in relation to post-traumatic stress symptoms (Brown et al., 2003; Kazak, 2001, 2004, 2005, 2006; Kazak et al., 1997, 1999; Kazak et al., 2002; Kazak et al. 2004b, 2005b). Further,

childhood cancer researchers have previously advocated for family level intervention based on family systems and social ecology theoretical frameworks (Kazak, 1997, 2001, 2004, 2006; Kazak et al., 2002; Simms & Kazak, 1998).

There are significant health care costs associated with not addressing the illness suffering of families in the midst of illness. For families in this research, it was very important that nurses and other health care professionals learn from the experience of suffering that the families lived through during and following cancer treatment. They believed that if they had received this family systems nursing intervention during treatment, it would have prevented much of the suffering they experienced during and following their child's treatment for cancer.

> *Jan (mother): …if somebody can learn from this…*

> *Ben (father): Especially with what we went through with the FNU. Had we been able to engage in that process during treatment, I think it might have really stopped what we went through afterwards.*

Application: Understanding the Implications for Nursing Practice, Education and Research

For Gadamer (1989), "the text…if it is to be understood properly – i.e. according to the claim it makes – must be understood at every moment, in every concrete situation, in a new and different way. Understanding here is always application" (p. 309). Within the process of interpretation, one comes to understand the topic of the inquiry in a new and different way, and that difference should be evidenced within the written account of the interpretation. Yet also, an interpretation must be left open to being engaged differently by those who come to read it in the future. As such, part of the responsibility of application lies with those who take up the interpretation, those who come to read it, and engage in conversation with it. How does it speak to the nursing practice they know,

how does it change understanding of their nursing practice? What new possibilities for nursing practice does it invite? Madison (1988) claimed that

> all interpretation works under the promise of truth….knowledge is not so different from faith. When we opt for a given interpretation, we do not do so because we know it to be true…but because we *believe* it to be the best, the one that offers the most promise and is the most likely to make the text intelligible, comprehensible for us. (p. 15)

In considering how this interpretation may be read, or taken up in nursing practice, education, and research, there is a responsibility to account for some of the limitations that it inherently holds. One of the most important limitations of this interpretation is that it explored Family Systems Nursing intervention with children and families living with childhood cancer within a highly specific practice context: an educational/research practice setting that was unlike those that presently exist in health care settings today. The videotaped nursing intervention all occurred at the FNU, a research, education, and practice unit that existed for twenty five years at the Faculty of Nursing, University of Calgary under the directorship of Dr. Lorraine Wright, and then Dr. Janice Bell (Bell, 2008; Wright et al., 1990). Nurses, as well as other health care professionals, must decide in what ways this interpretation might inform their practice in other contexts where they are involved in the care of families living with childhood cancer.

Nevertheless, what limits this research is also what makes this research so unique within the field of childhood cancer. This is the only family intervention study within the field of childhood cancer that provides evidence of nursing intervention with the family based on a qualitative exploration of many hours of actual videotaped clinical work

guided by a previously researched intervention model for advanced nursing practice in Family Systems Nursing (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996). Rather than quantitative analysis of outcome data, it provides a qualitative exploration of the very process of family intervention, allowing for a retrospective analysis of the interactions shared by families and nurses within the intervention practice (Bell & Wright, 2007; Greenberg, 1986, 1991; Greenberg & Pinsof, 1986; Heatherington et al., 2005; Lebow, 1996; Pinsof, 1989; Pinsof & Wynne, 2000; Pinsof et al., 2009). Further, there has been very little research conducted on the practice of family intervention within this population. Although there are guidelines and recommendations for family-centred psychosocial care in pediatric cancer (Noll & Kazak, 2004; Kreitler & Weyl Ben Arush, 2004; Woodgate, West, & Wilkins, in press), there is very limited evidence regarding the consistent implementation of such guidelines across major treatment centres (Kazak, 2004).

Further limitations also exist within this research study. Two of the children had CNS tumors, and the other a solid abdominal tumor. The study is therefore limited by a focus on only two childhood cancer illness trajectories. The experiences of family members in other childhood cancer illness trajectories (ie. leukemia, Hodgkin's lymphoma, neuroblastoma) may be qualitatively different. The children and families who participated in the clinical intervention at the FNU may also have self-selected: they may have been families who were particularly open to this type of family level intervention. Also, there are limitations in relation to gender and the lack of cultural diversity. Within this study there was only one father who participated in a research interview, although within the videotaped clinical work, each family included a father, husband or male

partner. All of the families who participated in this research were Caucasian, thus limiting the findings in relation to more diverse cultural backgrounds.

Implications for Nursing Practice: Keeping the Family in Focus

Within the childhood cancer literature, there has been a growing appreciation of the need to better address holistic care for the entire family (Björk et al., 2005, 2009; Clarke-Steffen, 1990, 1993, 1997; Cornman, 1993; Freeman et al., 2000; Kazak, 2004; Kelly & Ganong, 2011; Koch, 1985; McGrath 2001a, 2001b; McGrath et al., 2004, 2005; Patterson et al., 2004; Tarr & Pickler, 1999; Woodgate, 2001, 2003, 2006a, 2006b; Woodgate & Degner, 2002, 2003b). With that understanding, different family theoretical frameworks have been proposed in an effort to guide the care of the family (Deatrick & Knafl, 1990; Deatrick et al., 2006; Knafl & Deatrick, 1990, 2003; Knafl, Breitmayer, Gallo, & Zoeller, 1996; Clarke-Steffen, 1990, 1993, 1997; McCubbin & McCubbin, 1993, 1996; Wright & Leahey, 2005, Wright & Bell, 2009; Wright et al., 1996). One of the conceptual frameworks that has been proposed for clinical assessment of the family and research with families within this particular population is the Family Management Style (FMS) Framework (Alderfer, 2006; Deatrick & Knafl, 1990; Deatrick, Mullaney, & Mooney-Doyle, 2009: Deatrick et al., 2006; Knafl & Deatrick, 1990, 2003, 2006; Knafl, Breitmayer, Gallo & Zoeller, 1996; Knafl, Deatrick, & Gallo, 2008; Ogle, 2006; Thibodeaux & Deatrick, 2007). This framework was developed from a long history of qualitative research with families of children living with serious pediatric illness, and has been previously adopted by qualitative nursing researchers in childhood cancer (Clarke-Steffen, 1990, 1993, 1997). Another conceptual framework which has emerged within the field of pediatric psycho-oncology care is the Resiliency Model of Family Stress,

Adjustment, and Adaptation (McCubbin & McCubbin, 1993, 1996). Similar to the Calgary Family Assessment and Intervention Models (Wright & Leahey, 2009), and the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996), this conceptual framework emphasizes family strength and resiliency in the context of childhood cancer. The limitation of both of these frameworks is that they are conceptual and theoretical frameworks: although useful in helping nurses to conceptualize the family experience in terms of family assessment and research, they are not clinical practice frameworks which can explicitly guide nursing practice focused on family intervention within childhood cancer.

The limited intervention research aimed at the family system in pediatric oncology has come primarily from a research group at the Children's Hospital of Philadelphia (Kazak, 2004, 2005, 2006; Kazak, Alderfer, Streisand et al., 2004; Kazak, Simms et al., 2005; Kazak et al., 1999, 2009). These researchers have been guided by a social ecology/family systems framework, and have conceptualized the diagnosis and treatment of childhood cancer as a "series of traumatic events that can result in posttraumatic stress symptoms (PTSS)" (Kazak, 2004, p. 143). Kazak and her colleagues (1999) have developed an intervention to reduce PTSS in adolescent survivors and their families through a program that includes cognitive, behavioral, and family therapy approaches within a one day program of intervention (Surviving Cancer Competently Intervention Program) (Kazak et al., 1999). They then expanded their work through an evaluation of a three-session intervention for parents/caregivers of newly diagnosed cancer patients (Kazak et al., 2005b).

In her analysis of the research on family assessment and intervention in pediatric oncology, Kazak (2004) suggested that one of the research priorities for family assessment and intervention should be the advancement of standards for evidence-based practice during cancer treatment. It was her assertion that intervention approaches shown to be helpful in research studies, be evaluated for use in clinic settings, and then translated more widely into pediatric oncology practice. The evidence within the present hermeneutic interpretation provides support for exploring further research on the implementation of Family Systems Nursing intervention guided by the IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996) within clinical pediatric oncology settings. In future research, it will be extremely important to study the translation of the interventional practices found to be the most helpful to families living with childhood cancer into clinical practice (Duhamel, 2010; Leahey & Svavarsdottir, 2008).

Seventeen years ago, Carole Robinson (1994, 1998) first studied the process of Family Systems Nursing intervention within the clinical practice setting of the FNU. From that research, the therapeutic value of bringing the family together for a therapeutic conversation about how illness was affecting family life and family relationships was seen as essential to addressing illness distress within chronic illness (Robinson & Wright, 1995). Other key interventional practices described in that research included the establishment of a therapeutic relationship between nurse and family, inviting meaningful conversation, noticing/distinguishing family and individual strengths, exploration of family concerns, and helping families to put illness/illness problems in their place (Robinson & Wright 1995). Despite these findings, as well as other research emerging

from the practice context of the FNU, to date family systemic nursing practice in the context of acute and community care settings is rarely occurring. Families living with childhood cancer are not receiving the assistance they require in relation to addressing the human suffering that is an inherent part of this illness experience. The present research study calls into question how we might re-frame clinical care so that the suffering of all family members may be addressed more comprehensively.

In Margaret Newman's (1994) nursing theory which describes health as expanding consciousness, what in part is highlighted is the importance of not reducing life situations or experiences of problems. Hartrick Doane and Varcoe (2005) articulated the influence this theory has in understanding relational nursing practice, as it "highlights the importance of nurses entering into the difficulty of families' health and healing experiences and 'hanging in there' with families as they live and experience uncertainty and chaos in their lives" (p. 106). What this research adds to nursing knowledge is how in actual clinical practice nurses can intervene to not only enter the difficulty with families, but also work to open up new understandings, beliefs, or interpretations of those difficulties.

The consideration of expanding this family intervention practice to clinical settings for further application in practice, education, and research raises new questions: what is the most efficient and thoughtful way to pursue this aspect of care? Should it be based in acute care, in hospital-based oncology programs, or would this nursing intervention be best provided within a community setting? Within the *Ottawa Charter for Health Promotion* (WHO, 1986), it was proposed that the reorientation of health services within health care reform would require a new conceptualization of how health care is

delivered, and a new conceptualization of who holds the responsibility for the delivery of

that care. It was suggested that the responsibility for health promotion in health care

service be shared between individuals, community groups, professionals, health service

institutions, and governments (WHO, 1986). It may be that the most appropriate place for

the development and researching of Family Systems Nursing intervention based on the

IBM (Bell & Wright, 2011; Wright & Bell, 2009; Wright et al., 1996) within this

particular population would be a hospital or community clinic setting developed through

a multi-sectoral partnership including interdisciplinary professionals from acute-care

based pediatric oncology programs, university-based academics with expertise in clinical

research, community groups and/or charitable foundations, as well as national

organizations such as the Canadian Cancer Society.

While working towards possibilities for intersectoral collaboration for family

intervention practice and research in the future, it may also be possible for pediatric

oncology programs to begin implementing some of the interventional practices found to

be helpful to families in this research within ambulatory acute care settings. Recently,

Duhamel and her colleagues (2007) reported on a qualitative evaluation of implementing

the Calgary Family Systems Nursing Approach (CFSNA) within an ambulatory care

setting with families living with adult congestive heart failure (CHF). Within this clinical

setting, a clinical nurse specialist who had completed graduate work in Family Systems

Nursing implemented a four session family intervention with adult patients and their

spouses. Similar to the findings in this research, the CHF families reported that part of

what was helpful to them in relation to this interventional approach was the

understanding they gained of each other's illness experience. Duhamel et al. (2007) described this as a revealing of suffering:

> meetings with the nurse permitted couples to exchange views on their illness experiences and clarify perceptions…it allowed the patients and the nurse to acknowledge the suffering the wives experienced, a suffering that is often ignored or passes unnoticed in the normal course of daily care. (p. 46)

Further, this research raises the possibility of potential application of this Family Systems Nursing intervention approach not only in families living with childhood cancer, but also with other pediatric life-threatening and chronic illnesses. There is a pressing need to translating knowledge from research studies such as this one into clinical practice yet one that is highly complex and challenging. Large and significant knowledge translation projects are emerging within the field of family nursing, and will provide guidance in the future for more effective translation of Family Systems Nursing intervention knowledge into clinical practice (Leahey & Svavarsdottir, 2009; Svavarsdottir, 2006, 2008).

Implications for Nursing Education

The findings within this research study bring into question how nurses are presently being educated in intervening with the family in the context of childhood cancer. Families in this research spoke about how the nurses they encountered in acute care settings did not address the illness suffering experienced by the family, but rather, focused primarily on the physical care of the ill child. Limited time, administrative influences on nursing care, as well as a lack of knowledge were identified by the families as some of the constraints that nurses faced in this regard. There is a need for more in

depth education about assessment and intervention with the family in the context of pediatric oncology nursing practice.

Recently, McLeod, Tapp, Moules, and Campbell (2010) reported findings from a study which qualitatively explored the family nursing practices in adult oncology, including ambulatory, outpatient, and palliative care settings. The questioning practices of oncology nurses were seen to be an integral part of family nursing practice, and there were times when nurses intentionally used their questioning practices to assist families in exploring the meanings of illness. However, often when sensitive or difficult topics arose, nurses lacked the confidence to move deeper into important conversations with family members. "Hearing comments such as "I'm scared" were experienced as burdensome, frightening, and perceived to mean that the nurse must do something rather than simply be with the family in their questioning and uncertainty" (p. 98).

There is clearly a need for Family Systems Nursing education for nurses in the context of clinical care, as well as in undergraduate and graduate nursing education. Beyond education, nurses also need mentorship and support in developing their theoretical and practice knowledge within this specialization. Previous Family Systems Nursing scholars have researched and documented specific guidelines and educational approaches for education in Family Systems Nursing (Flowers et al, 2008; Moules & Johnstone, 2010; Moules & Tapp, 2003; Tapp & Wright, 1996). These pedagogical approaches, in combination with the practice models available to guide nursing practice in this area of specialization, provide nurses with extremely helpful resources to move their practice with families forward in a different way.

In her discussion of evidence-based assessment, intervention, and psychosocial care in pediatric oncology, Kazak et al. (2007) proposed that rather than working in a consultative role, pediatric psychologists need to be "embedded" (p. 1106) within interdisciplinary treatment teams, allowing for more comprehensive development of family intervention, and collaborative partnerships to expand education, practice, and research (Kazak et al., 2007). This may be a model that could be effective for the development of Family Systems Nursing in pediatric oncology. The embedding of nurses with advanced nursing practice education in Family Systems Nursing would help to provide the support and mentorship needed to advance care of the entire family within the field of childhood cancer.

Future Nursing Research: Family Experiences of Loss and Grief in the Midst of Childhood Cancer

In chapter seven of this research thesis, I explored the illness, anticipatory, and survivor grief that families experience in relation to the losses which are an inherent part of living with childhood cancer. Based on an etymological exploration of the word suffer, it was suggested that we could understand suffering to be the sustaining of loss; to undergo, endure, bear, or carry grief. An emerging body of qualitative research within the field of childhood cancer has begun to articulate the layers of loss and grief experienced by family members in the context of childhood cancer treatment (Björk et al., 2005; Brody & Simmons, 2007; Chen et al., 1987; Clarke-Steffen, 1990, 1993, 1997; Cornman, 1993; De Graves & Arunda, 2008; Enskär, Carlsson, Golsater, Hamrin, et al., 1997; Freeman et al., 2000; Iles, 1979; Koch, 1985; Kramer, 1984; McCubbin et al., 2002; McGrath et al., 2004, 2005; Patterson et al., 2004; Sidhu et al., 2005; Tarr & Pickler, 1999; Woodgate, 2001, 2006a; Woodgate & Degner 2002, 2003b, 2004).

I suggested within chapter seven that the Dual Process Model of Coping with Bereavement (DPM) (Stroebe & Schut, 1999, 2001) is one contemporary grief/bereavement model that might be helpful for understanding and conceptualizing grief within pediatric life-threatening illnesses such as cancer. Further, it is a model which would be congruent with family intervention based on the IBM (Wright & Bell, 2009; Wright et al., 1996). Within each of these models, there is an emphasis on acknowledging and privileging suffering and loss while simultaneously addressing experiences of family strength, hope, and moving forward in life. Each of the grief experiences described within this research thesis need to be explored further within research studies in an effort to articulate better the unique aspects of loss and grief for families living with childhood cancer. In particular, there is a need to delineate grief which has an anticipatory character more carefully from illness grief which is related to losses that have already occurred within the context of living with illness.

Based on the family experiences of illness grief described in this research, it has been suggested that the loss orientation within the DPM be modified for the potential application of this model in pediatric life-threatening illness. The loss orientation would need to focus on processing the many different losses discussed within chapter seven of this research thesis. In terms of the grief experienced by families living with childhood cancer, the focus was not on the processing of a death, but rather, on processing the losses which were a part of having a child diagnosed and treated for cancer. These included the loss of family normalcy, physical, relational, and symbolic losses (Doka, 1989, 2002; Rando, 1984, 2000; Roos, 2002), as well as anticipatory (Rando, 1984, 2000) and illness survivor grief (see Figure 3).

Future Nursing Research: Parenting in the Context of Pediatric Serious Life-Threatening Illness

What emerged in the process of this inquiry was evidence of illness suffering at the family level, but also suffering that was unique to particular family subsystems. Mothers and fathers experienced a unique type of suffering in relation to the diagnosis and treatment of a child with cancer. Within this research thesis, I have explored how parenting, a once taken-for-granted experience, is profoundly altered by the entrance of childhood cancer. Parents struggle with how best to parent the ill child, as well as parent the healthy brothers and sisters in the family. Some parents may carry the belief that their role as a parent is to protect their children from harm, and these beliefs can invite experiences of guilt, blame, and failure in parents. It is important that nurses in clinical practice have sensitivity about how some of these illness beliefs may invite and sustain experiences of suffering within the parental subsystem.

The parenting challenges experienced by mothers and fathers persisted not only throughout the duration of cancer treatment, but also in the months and years after the completion of treatment. Parents reported an ongoing lack of confidence in their parenting, and education for parents in the context of pediatric life-threatening illness was identified as one of the areas where further assistance is needed. In relation to the family intervention at the FNU, one of the mothers reported that although she found the intervention process very helpful, she would have appreciated more specific guidance in relation to her day to day parenting practices. These reported challenges in parenting are supported by previous research within the field of childhood cancer (Brody & Simmons, 2007; Lillrank, 2002; McGrath, 2001a; McGrath et al., 2005; Patterson et al., 2004; Young, Dixon-Woods, & Heney, 2002; Young, Dixon-Woods, Findlay et al., 2002;

Woodgate 2001, 2006a; Woodgate & Degner, 2003b, 2004), and highlight an important area for further research in the future.

Future Nursing Research: The Illness Suffering of Brothers and Sisters

Another aspect of illness suffering that has been highlighted within the findings of this research is the unique loss and suffering experienced by brothers and sisters in the context of childhood cancer. Healthy siblings face the loss of time and attention from their parents, and at times, they can feel excluded from the family unit. These findings are supported by previous research within the field of childhood cancer, which have highlighted the distress experienced by siblings in relation to the profound changes to family roles, routines, and relationships (Barbarin et al., 1995; Barrera, 2000; Bendor, 1990; Chesler et al., 1991; Freeman et al., 2000; Gogan & Slavin, 1981; Havermans & Eiser, 1994; Iles, 1979; Kramer, 1984; Martinson, Gillis, Colaizzo, Freeman, & Bossart, 1990; Sargent et al., 1995; Shapiro & Brack, 1994; Sloper, 2000a; Woodgate 2001, 2006b). Woodgate (2006b) recently has described the great burden that siblings carry in witnessing the illness suffering of other family members, and the enduring sadness that they experience in relation to illness. In Woodgate's research (2006b), the sadness experienced by siblings was not often recognized by other family members: "to some extent, the sadness was an "unspeakable sadness": as the siblings were more than often silent about their sadness" (p. 16).

Similarly, in this research, brothers and sisters had lived a life largely separated from the ill child and their parents during cancer treatment, and prior to coming to speak with the nurses at the FNU as a family, they had not had the opportunity to voice their unique experiences of suffering. Further, parents had not been able to appreciate or hear

siblings' experiences of illness suffering in the manner that was made possible during the clinical intervention. The Family Systems Nursing intervention practice of inviting and assisting family members to bear witness and give testimony to one another's illness suffering was particularly helpful in addressing the sadness, loss, and grief of brothers and sisters. Further research is needed in relation to the illness suffering that is unique to brothers and sisters, to the relational changes they experience in family life, as well as to the possibilities for family intervention in relation to their unique experiences of suffering.

Conclusion

As I come to the conclusion of this hermeneutic inquiry, what remains is an accounting for how I have been changed in the process of this research, how the horizon I entered this inquiry with has been opened, challenged, and expanded. Smith (1991) suggested that

> the conversational quality of hermeneutic truth points to the requirement that
>
> any study carried out in the name of hermeneutics should provide a report
>
> of the researcher's own transformations undergone in the process of inquiry;
>
> a showing of the dialogical journey, we might call it. Underscored here is a
>
> profoundly ethical aspect to hermeneutic inquiry in a life-world sense; namely,
>
> a requirement that a researcher be prepared to deepen her or his own self-
>
> understanding in the course of the research. (p. 198)

It may not be possible within this space, or within the written word, to account for all of the transformations, or new understandings that I have experienced within the course of this inquiry. To attempt an account, I must return to the address that led to this inquiry. I have stood beside many families as their children were diagnosed with cancer, have

undergone treatment for cancer, entered survivorship, or faced death. Within those experiences, I have struggled with the illness suffering that I have witnessed, and my inability to relieve or alleviate that suffering in a more comprehensive manner. I recall the words of a mother whom I met in my practice many years ago. I was a young nurse, and new to the world of oncology. I was on my way into another patient room when this mother stopped me in the hallway. She touched my arm, looked into my eyes, and asked me the following question: "how does a mother bear this?" At that moment, I did not have an answer for her, I had no sense of how to respond, of what might be healing for her, or what might be most compassionate in that moment of conversation.

The embracing of this topic, the illness suffering of family members in childhood cancer, as well as a hermeneutic research approach, may have occurred in part because I was searching for answers to questions such as these: How does a parent bear this? Why me? Why our family? Underlying the need for answers may have been the desire to alleviate the suffering of families in the context of living with childhood cancer, to make the world a safe place once more, for them, as well as for myself. Several months ago, I presented part of this hermeneutic interpretation at a scholarly conference. John Caputo, a hermeneutic philosopher who was the invited guest speaker, quietly reminded me at the end of my presentation to remember that the world is not a safe place. The world is never a safe place. There is a strong, instinctual longing within us to want to believe the world is a safe place, to believe that it is possible to help children and families return to a world in which they are once again safe, a place where cancer has been conquered. Yet, what I have been asked to face within the process of this inquiry is the impossibility of returning to that place of safety. I have become more keenly aware of how the opening and

narrowing of the spirit is a fundamental aspect of human life; each of us will face that narrowing and opening, although it will show itself in different forms within different lives. What the illness suffering of these families have brought me to, in part, is a desire to reach for the opening to the other (Frank, 1995), when the experiences of my own life, both professional and personal, lead to its very narrowing.

Families did experience healing as they participated in clinical intervention at the FNU, but what seemed to be important within the process of family intervention, was not so much the resolution or alleviation of suffering, but the willingness of the nurses to share or encounter the suffering that families faced, and to assist family members in the sharing and exploration of their suffering with one another. It may be that it is not the answers or meaning associated with the often internalized "suffering questions" (Wright, 2008, p. 404) asked by family members that is most needed, or even possible, but rather, what is most helpful may be the creation of relational space in which these questions can be asked and held in the presence of one another; this may then open the possibility of new interpretations and understandings. Frank (1995) suggested that "remaking begins when suffering becomes an opening to others" (p. 176). Drawing on the writing of Lévinas, Frank (1995) asserted:

> that suffering becomes "the possibility of half opening" to the other…this opening does not give meaning to the nameless suffering, but neither does that suffering remain useless. The meaning and the just suffering are experienced by the witness...the "inter-human" opens up when suffering becomes the call and response implicating self and other…Lévinas's most important lesson is that for everyone rendered "other" by suffering who speaks, perhaps in that act of witness,

some nameless suffering is opened. The suffering person is always the other,

reduced and isolated. To tell any story of suffering is to claim some relation to the

inter-human. Any testimony is a response to the half opening of nameless

suffering. (pp. 179-180)

In understanding this opening as a half-opening, Frank and Lévinas ask us "to remember

the suffering that remains useless, nameless, and untouched: useless, but also, in its call

to others, not useless…the voiceless are given a voice" (Frank, 1995, p. 180). When

families living with childhood cancer enter therapeutic conversations, and suffering is

called forward in the form of illness testimony, there lies the possibility of a half opening,

suffering which was nameless and voiceless, may be given a voice, shared between nurse

and family, between family members, and this in turn can lead to an opening for the

offering of new perspectives, understandings, and interpretations of this suffering.

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APPENDIX A

Inclusion and Exclusion Criteria

Outlined below are the inclusion and exclusion criteria for child, sibling and parent and nurse clinician participants in this research study.

Children with Cancer who:

1. Have received a diagnosis of cancer (no particular type of cancer or stage of disease).

2. Have received therapeutic family intervention based on the IBM (Wright et al., 1996) at the FNU, Faculty of Nursing, University of Calgary [therapeutic nursing conversations].

3. Are at least 6 months from receiving a diagnosis of cancer, and who are within one year of completing cancer treatment at the time of the first clinical session at the FNU.

4. Parent/legal guardian has provided written and verbal consent for their children's participation in this research study.

5. Voluntarily have provided verbal assent to participate in clinical sessions at the FNU, as well as written and verbal assent to participate in individual and/or family research interviews following the completion of clinical work at the FNU.

6. Are seven years of age or older.

7. Understand and speak English.

Parents/Legal Guardians of Children with Cancer who:

1. Have received therapeutic family intervention based on the IBM (Wright et al., 1996) at the FNU, Faculty of Nursing, University of Calgary [therapeutic nursing conversations].

3. Voluntarily have provided written and verbal consent to participate in clinical sessions at the FNU, as well as voluntary written and verbal consent to participate in individual and/or family research interviews following the completion of clinical work at the FNU.

4. Understand and speak English.

Siblings of Children with Cancer who:

1. Have received therapeutic family intervention based on the IBM (Wright et al., 1996) at the FNU, Faculty of Nursing, University of Calgary [therapeutic nursing conversations].

2. Parent/legal guardian has provided written and verbal consent for their children's participation in this research study.

3. Voluntarily have provided verbal assent to participate in clinical sessions at the FNU, as well as written and verbal assent to participate in individual and/or family research interviews following the completion of clinical work at the FNU.

4. Are seven years of age or older. Siblings of children with cancer who are younger than six years old will not be asked to participate in research interviews, but parents will be asked for their voluntary and written consent for them to be involved in clinical sessions at the FNU and for the videotapes of clinical work with those siblings to be included in this research study.

5. Understand and speak English.

Nurse Clinicians who:

1. Conducted the clinical sessions based on the IBM (Wright et al., 1996) with children with cancer, their siblings and/or their parents/legal guardians at the FNU, Faculty of Nursing, University of Calgary.

2. Voluntarily have provided verbal and written consent to participate in research interviews following completion of clinical sessions with family research participants included in this research study.

3. Understand and speak English.

APPENDIX B

PARENTS' OR LEGAL GUARDIANS' PEDIATRIC INFORMED CONSENT

TITLE: Addressing Illness Suffering in Childhood Cancer: Exploring the Beliefs of Family Members in Therapeutic Nursing Conversations

RESEARCHER: Christina West, RN, MN, PhD Student (Faculty of Nursing, University of Calgary)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your child's participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

This research study will explore the conversations about illness that nurses at the Family Nursing Unit (University of Calgary) share with families who have had a child diagnosed with cancer. Previous research done by nurses working and studying at the Family Nursing Unit, has shown that when one family member has a serious illness, then all members of a family experience changes in family life and can suffer in living with illness and the changes it has brought. Clinical practice and research in the Family Nursing Unit has also shown that when nurses enter into purposeful conversations with families about how illness has affected them and the relationships they share with one another, about what different family members believe about illness, then the illness suffering families experience can be lessened.

Four to five families who have a child diagnosed with cancer and have participated in conversations with nurses at the Family Nursing Unit (University of Calgary) will be asked to participate in this research study.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to better understand the family experience of living with childhood cancer, and in particular, the ways in which conversations with nurses at the Family Nursing Unit have been helpful to children living with cancer, their brothers and sisters, as well as their parents. This study is expected to contribute to our understanding of how nurses, social workers, doctors and other health care professionals may enter into purposeful conversations with families living with childhood cancer in ways that may hold the potential for lessening the illness suffering experienced by family members.

The completion of this research study will be part of Christina's work as a doctoral

student in the Faculty of Nursing, University of Calgary. This research will be overseen by her doctoral supervisor, Dr. Janice Bell who is an Associate Professor at the Faculty of Nursing, University of Calgary and Director of the Family Nursing Unit. As well, the research will be supervised and guided by Nancy Moules, RN, PhD, Associate Professor, Faculty of Nursing, University of Calgary and Roberta Woodgate, RN, PhD, Associate Professor, Faculty of Nursing, University of Manitoba.

WHAT WOULD MY FAMILY HAVE TO DO?

If you agree to participate in this study, you and other members of your family will be asked to take part in one or more interviews with Christina West, RN. If you agree, the children in your family who are seven years of age or older, will also be asked to participate in this study. You will have the choice of whether you would like to participate in the interviews with Christina together as a family, or individually. Each interview will likely take one to two hours of your time, and will be conducted in your home or another place of your choice. The interviews will take place at a time that is convenient for you, and with your consent the interviews will be audio-taped.

Questions during the interviews will focus on your experience of living with childhood cancer and the conversations you shared with nurses about this illness experience during the clinical work you participated in at the Family Nursing Unit (University of Calgary). Your understandings of how the conversations with nurses were helpful, what they meant to your family, and how they may or may not have affected your family will be part of the interview. You may also be asked how the conversations you shared with nurses at the Family Nursing Unit were different from the conversations you have shared with other health care professionals who have been involved in the care of your child and family.

WHAT ARE THE RISKS?

It is possible that some of the questions asked within the interview(s) may raise some emotional topics for you or other members of your family. In this event, and if you or other members of your family desire, information will be available regarding the support and/or resources available to you.

ARE THERE ANY BENEFITS FOR MY CHILD?

If you agree to participate in this study, and/or agree to have your children participate in this study, there may or may not be a direct benefit to you or your child. The understanding gained in this study may help guide nurses and other health care professionals in how to enter into purposeful conversations with family members about the experience of living with childhood cancer and the suffering families experience as a part of this illness.

DOES MY CHILD HAVE TO PARTICIPATE?

Participation in this study is completely voluntary. Even if you give permission for your own participation, and/or for your children to participate in this study, the children themselves must also agree to participate. If you and your children decide to participate in this study, you or your child may also withdraw at any time and/or refrain from answering any questions you prefer to omit, without any consequence. Your child's health care will not be affected in any way if you or your child decide to withdraw from this study. Your child may withdraw from the study by speaking to you or directly to Christina West. Christina may also withdraw your child from the study if necessary.

WHAT ELSE DOES MY FAMILY'S PARTICIPATION INVOLVE?

The findings from this study may be presented at a health conference or published in a journal. In all instances, your family's and child's identity would not be discussed or revealed to anyone.

WILL WE BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

Any parking costs that your family incurs because of participation in this study will be covered by the researcher.

WILL MY FAMILY'S RECORDS BE KEPT PRIVATE?

All information that you or your children provide as part of the interviews in this study will remain confidential. Confidentiality will be maintained at all times except in situations in which there is a legal requirement to disclose identity (i.e. abuse situations). Your family's and child's identity will remain anonymous and any identifying data will be removed. The interview information will be transcribed from the audiotapes to a written document and participants will be assigned fictitious names. Only Christina West her supervisor, Dr. Janice Bell, as well as Dr. Nancy Moules and Dr. Roberta Woodgate will have access to the data obtained during this research study. Your name or the name of your children will not be on this research data, but will have been replaced by a study number and a fictitious name. During this research study, all data will be stored in a locked cupboard in the Family Nursing Unit and computer protected by a password known only to Christina. Once the study is completed, all data will be stored under lock and key in a filing cabinet at the Family Nursing Unit, University of Calgary for a period of 7 years following completion of this study.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child's participation in the research project and agree to their participation as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw your child from the study at any time without jeopardizing their health care. If you have further questions concerning matters related to this research, please contact:

<div align="center">

Christina West, RN, MN, PhD Student
Faculty of Nursing, University of Calgary
(403) 220-4647
Email: chwest@ucalgary.ca

or

Janice Bell, RN, PhD
Associate Professor
Director, Family Nursing Unit
Faculty of Nursing University of Calgary
(403) 220-4647

</div>

If you have any questions concerning your child's rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

_____   _____
Parent/Guardian's Name   Signature and Date

_____   _____
Child's Name   Signature and Date

_____   _____
Investigator/Delegate's Name   Signature and Date

_____   _____
Witness' Name   Signature and Date

The investigator or a member of the research team will, as appropriate, explain to your child the research and his or her involvement. They will seek your child's ongoing cooperation throughout the study.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX C

PEDIATRIC ASSENT FORM FOR CHILDREN
(BROTHERS and SISTERS)

RESEARCH PROJECT TITLE: Addressing Illness Suffering in Childhood Cancer: Exploring the Beliefs of Family Members in Therapeutic Nursing Conversations

RESEARCHER: Christina West, RN, MN, PhD Student (Faculty of Nursing, University of Calgary)

I,_____, state that I am _____years of age and wish to take part in the above project. I understand that the goal of this project is to help nurses better understand how to help kids who have cancer, their brothers, sisters, and parents by understanding what is really difficult for them in living with cancer. A s well, I understand that Christina hopes to learn how talking with the nurses at the Family Nursing Unit may or may not have been helpful for me and my family. I understand other children who have a brother or sister with cancer and who have come to talk with the nurses at the Family Nursing Unit will also participate in this project. The children from four to five families who have come to talk with the nurses at the Family Nursing Unit will be participating.

For this project, I will be asked to take part in one or more interviews with Christina, the nurse who is doing this project. I understand that I will have the choice to talk with Christina on my own, or with other members of my family. The interviews will take about one to two hours to complete. I understand that in the interviews I will be asked questions about what it is like to have a brother or sister with cancer, and what it was like to talk with nurses at the Family Nursing Unit about this. I also understand that I will be asked about how my family has changed since cancer, and what might have helped my family in coming to talk with the nurses at the Family Nursing Unit. I understand that the interviews will be tape recorded and that Christina will not tell anybody about how I answered the questions. I understand that my name will be erased from all the interviews, and the information will be assigned to a "pretend" name. If I would like, I can help Christina choose a pretend name for the information I give to her in this project.

I understand that taking part in this project is my choice and that if I decide not to be in the project, no one will get mad at me. I understand that even if I first decide to be in it, I can still quit at any time. I understand that I can quit either by telling Christina or by telling my parents that I no longer want to be in the project.

I understand that nothing in the study will be done to me that could hurt me. However, I understand that if I become sad or mad, I may ask for help or may need to talk to my parents or someone else.

I understand that Christina may write a paper about the project or do a presentation so that others can learn about it. I may ask Christina to tell me what she learned from the project.

I understand that if I have any questions about the project at any time, I may ask Christina or my parents.

I understand that it is up to me if I want to be in this project. I have read the information and Christina has also read it to me.

_____   _____

   Child's Signature   Date

_____   _____

   Signature of Researcher   Date

....

APPENDIX D

NURSE CLINICIAN (FAMILY NURSING UNIT) INFORMED CONSENT

TITLE: Addressing Family Suffering in Childhood Cancer: Exploring Family Beliefs in Therapeutic Conversations

RESEARCHER: Christina West, RN, MN, PhD Student (Faculty of Nursing, University of Calgary)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

The Family Nursing Unit was established at the Faculty of Nursing, University of Calgary in 1982. It is an outpatient nursing clinic for families suffering with serious illness. Previous research done by nurses working and studying at the Family Nursing Unit has shown that when one family member has a serious illness, then all members of a family experience changes in family life and can suffer in living with illness and the changes it has brought. Clinical practice and research in the Family Nursing Unit has also shown that when nurses enter into purposeful conversations with families about how illness has affected them and the relationships they share with one another, and about what different family members believe about illness, then the illness suffering families experience can be lessened. This research study will explore the therapeutic illness conversations that nurses at the Family Nursing Unit share with families who have had a child diagnosed with cancer.

Four to five families who have a child diagnosed with cancer will be asked to participate in this research study.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to better understand the family experience of living with childhood cancer, and in particular, the ways in which therapeutic illness conversations with nurses at the Family Nursing Unit may be helpful to children living with cancer, their brothers and sisters, as well as their parents. This study is expected to contribute to our understanding of how nurses, social workers, doctors and other health care professionals may enter into purposeful conversations with families living with childhood cancer in ways that may hold the potential for lessening the illness suffering experienced by family members.

In particular it will aim to explore the following two research questions: What questions do ill children, siblings and parents ask themselves as they experience physical, emotional and/or spiritual suffering in living with childhood cancer? When nurses explore the suffering of family members by entering into therapeutic illness conversations based on the Illness Beliefs Model (Wright, Watson & Bell, 1996), is there lessening of illness suffering, and what difference do these conversations make for children and families living with cancer?

The completion of this research study will be part of Christina's work as a doctoral student in the Faculty of Nursing, University of Calgary. This research will be overseen by her doctoral supervisor, Dr. Janice Bell who is an Associate Professor at the Faculty of Nursing, University of Calgary and Director of the Family Nursing Unit. As well, the research will be supervised and guided by Nancy Moules, RN, PhD, Associate Professor, Faculty of Nursing, University of Calgary and Roberta Woodgate, RN, PhD, Associate Professor, Faculty of Nursing, University of Manitoba.

WHAT WOULD I HAVE TO DO IF I AGREE TO PARTICIPATE IN THIS RESEARCH STUDY?

If you agree to participate in this research study, you will be asked to take part in at least one research interview, with the possibility of a second interview with Christina. The research interview(s) will focus on your experience of conducting therapeutic illness conversations, based on the Illness Beliefs Model (Wright, Watson & Bell, 1996), with a particular family at the Family Nursing Unit, University of Calgary. Each research interview will likely take one to two hours of your time, and will be conducted in your home or another place of your choice. The research interview(s) will take place at a time that is convenient for you, and with your consent they will be audio-taped.

You are also being asked to consent to the use of the videotaping of your participation in clinical presessions, intersessions, and postsessions in which you shared your ideas with family members and the members of the clinical nursing team. Further, you are being asked to consent to the use of the written clinical documentation and therapeutic letters which were part of the clinical work with the family research participant(s).

WHAT ARE THE RISKS?

There are no expected risks to you in participating in this research study.

DO I HAVE TO PARTICIPATE?

Participation in this study is completely voluntary. If you decide to participate in this study, you may also withdraw at any time and/or refrain from answering any questions you prefer to omit, without any consequence. You may withdraw from the study by speaking to Christina West.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

The findings from this study may be presented at a health conference or published in a journal. In all instances, your identity would not be discussed or revealed to anyone.

WILL WE BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

Any parking costs that you incur because of participation in this study will be covered by the researcher.

WILL MY RECORDS/INFORMATION SHARED BE KEPT PRIVATE?

All information that you provide as part of the research interview(s) in this study will remain confidential. As well, information from the videotapes of clinical work at the Family Nursing Unit, the written documentation and letters will remain confidential. Your identity will remain anonymous and any identifying data will be removed. The research interview information will be transcribed from the audiotapes to a written document and participants will be assigned fictitious names. Only Christina West her supervisor, Dr. Janice Bell, as well as Dr. Nancy Moules and Dr. Roberta Woodgate will have access to the data obtained during this research study. Your name will not be on the research data, but will be replaced by a study number and a fictitious name. During this research study, all data will be stored in a locked cupboard or on a computer protected by a password known only to Christina. Once the study is completed, all research interview data will be stored under lock and key in a filing cabinet at the Family Nursing Unit for a period of 7 years, and then will be destroyed as per university policy.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child's and family's participation in the research project and agree to your child's and family's participation as research subjects. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw your child from the study at any time without jeopardizing their health care. If you have further questions concerning matters related to this research, please contact:

<div align="center">

Christina West, RN, MN, PhD Student
Faculty of Nursing, University of Calgary
(403) 220-4647
Email: chwest@ucalgary.ca

or

</div>

Janice Bell, RN, PhD
Associate Professor
Director, Family Nursing Unit
Faculty of Nursing University of Calgary
(403) 220-4647

If you have any questions concerning your child's rights as a possible participant in this research, please contact Bonnie Scherrer, the Ethics Resource Officer, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's Name	Signature and Date

Investigator/Delegate's Name	Signature and Date

Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX E

GUIDING QUESTIONS FOR PARENTS OF CHILDREN WITH CANCER

1. Could you tell me about your family's experience of living with cancer from the time your child was first diagnosed up until now?

2. Looking back, and thinking about how it has been for your family to live with cancer, what have been the most difficult times for you [your family]?

3. When you think about those times, the times when it has been most difficult for your family, who in your family do you think has had the hardest time?

4. Are there any questions that you ask yourself inside about your child having cancer? Are there questions you think other people in your family might be asking themselves inside?

Now, I'd like to spend some time talking about what it was like for your family to come and talk with the nurses at the Family Nursing Unit (FNU):

5. Could you talk a little bit about how your family came to visit the FNU. What was it like for you and your family to talk with the nurses at the FNU?

6. Could you tell me about the conversations you had with the nurses at the FNU? Of all the conversations you shared with the nurses at the FNU, which were most helpful to you [your family]?

7. We talked about the really difficult times that you and your family have had in living with cancer. Did talking with the nurses at the FNU help you with those difficult times? How do you think the conversations with the nurses at the FNU helped you with those times/things? If you could pick just one thing you talked about with the nurses at the FNU, the thing that helped you and your family with the really difficult parts/times of cancer…what would that one thing be? How did talking about that help you [your family]?

8. Were the conversations you shared with the nurses at the FNU different from those you have shared with the nurses, doctors and social workers who care for your child at the hospital? How were they different?

9. Could you tell me what was most helpful about the conversations you shared with the nurses at the FNU?

10. Could you talk about what was least helpful about the conversations you shared with the nurses at the FNU?

11. Is there anything else you can tell me about your [your family's] experience with coming to talk to the nurses at the FNU that you think it is important for me to know?

APPENDIX F

GUIDING QUESTIONS FOR SIBLINGS OF CHILDREN WITH CANCER

1. Could you tell me about what it has been like for you and your family since your brother/sister got cancer….from when you first found out up until now?

2. When you think about your brother/sister having cancer, what have been the hardest times for you [your family]?

3. In those really difficult times, who in your family do you think has had the hardest time?

4. Are there any questions that you ask inside about your brother or sister having cancer? Are there questions you think other people in your family might be asking inside?

Now I'd like to talk with you a little bit about the time when you and your family came to talk with the nurses at the Family Nursing Unit (FNU):

5. Could you tell me about why you and your family came to talk with the nurses at the FNU? What was it like to talk with the nurses there?

6. Could you tell me about the kinds of things that you and your family talked about with the nurses at the FNU? When you think about all the different things you talked about at the FNU, what helped you [your family] the most?

7. We talked about the really hard times that you and your family have had with cancer.   Did talking with the nurses at the FNU help you with those hard things/times? How do you think talking with the nurses helped you with those hard things/times? If you could pick just one thing you talked about with the nurses at the FNU, the thing that helped you and your family with the very hard parts of cancer….what would that one thing be? How did talking about that help you [your family]?

8. Was talking to the nurses at the FNU different from talking with the nurses at the hospital? What was different about it?

9. Could you tell me what was most helpful about talking with the nurses at the FNU?

10. Could you tell me what was least helpful about talking with the nurses at the FNU?

11. Is there anything else you think it's important to tell me about what it was like for you [and/or your family] to come and talk with the nurses at the FNU?

APPENDIX G

GUIDING QUESTIONS FOR FAMILY NURSING UNIT NURSE CLINICIANS

1. Could you tell me about your experience of entering into therapeutic conversations with the _____ family during their time at the FNU.

2. When you think back to the difficulties that you spoke with this family about in the context of their experience of living with childhood cancer, what most stands out for you?

3. Could you talk about what you remember being most helpful to this family in the therapeutic work at the FNU?

4. Could you talk about what your remember being least helpful to this family in the therapeutic work at the FNU?

I have chosen some videotape segments of the therapeutic conversation you shared with this family. I'd like us to watch them together, and then talk about them:

5. What do you recall about this aspect of the clinical work with the _____family? What were your hopes and thoughts behind asking that question of the family? Could you tell me what you experienced as the nurse clinician in this interaction with the family? Could you talk about how this interaction influenced the whole of the clinical work? Your understanding of the difficulties this family was facing?

6. Could you talk about how in this segment of conversation with the family, you were guided by the IBM (Wright et al., 1996)?

I have chosen a therapeutic letter that was part of the clinical work to this family. I'd like to read them to you, and then talk about it together.

7. Could you talk about what you remember about this letter? About the decision to send the letter….how it fit into the context of the clinical work? What were your hopes for this letter? Could you talk about the response the family had to the letter?

8. What is the one thing you will never forget about your work with the _____ family?

9. Based on the therapeutic conversations you shared with this family, what advice would you have for nurses and other health care professionals working with children and families in the context of childhood cancer?

10. Are there events in the therapeutic conversation you shared with this family that you remember as being central to the process of change that we have not talked about/viewed today? Could you talk about those conversation segments?

APPENDIX H

Therapeutic Letter: Second Research Family

November 2004

████ ████

Address

Dear ████:

Greetings from the Family Nursing Unit! Thank you for choosing the Family Nursing Unit in 1996/1997 and again this fall as a place to find healing. You met with us on October __, 2004 and we wanted to share some of our thoughts and impressions in a letter.

We are profoundly moved by your articulate and poignant descriptions of the many ways that serious illness has created challenges and losses for your family over the past 12 years. ████, we heard you describe this experience as being a relentless journey with signposts of sadness, unhappiness, loneliness, and struggle. With sadness, we heard the many ways that your metaphoric "journey to Disneyland" has been abruptly interrupted by serious illness, leading you to feel stuck in the mire at the side of the road, lost in the confusion, and doubting your ability to recommence your journey. We also heard about your successful, unrelenting determination to parent your daughter well and to do all in your power to secure the necessary care she requires. We were pleased to meet your daughter, ████, and witness the deep and unique connection and love between you.

In our last session together, you named your present suffering, "depression." In our attempts to make sense of your experience, we wondered if your suffering might be called something beyond depression, such as something called "grief." In our work with families at the Family Nursing Unit, we have come to understand grief as a profound spiritual experience that is a lifelong and life-changing experience. As a result, we have come to believe that the work of grief may not only focus on saying "goodbye" to what is lost, but may also include the formation of new relationships with what has been lost – in the very ways that you have found to say goodbye to the dream of the daughter you thought you might once have, and embrace and love the daughter you do have. Might there be anything useful to you in the reconceptualization of your suffering as as a grief that you have well deserved to claim, rather than a diagnosis of something? Does thinking of what you are experiencing as grief help you regard what you are feeling and knowing in your life as something normal rather than abnormal?

As you requested readings about grief, we have enclosed one article written by Dr. Moules and Dr. Bell and their colleagues. Perhaps this reading may offer you the opportunity to examine your own ideas about grief.

We were struck with your family's resourcefulness in considering the possibility of ▮▮▮ coming to a session at the Family Nursing Unit. We were taken by your description of ▮▮ as your "best friend" and believe that ▮▮'s ability to provide support and help to you is a tremendous gift. We welcome an opportunity to meet ▮▮ and learn from him about the ways that you support each other during this difficult time.

We appreciate the opportunity to work with your family and look forward to continuing our work together with you (and ▮▮ if he is able to join the session) on November ___ at 4pm.

With warm regards,

_____, 2nd year Master's student
Dr. Bell, RN, PhD, Director of the Family Nursing Unit
And other members of the clinical team.